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# Delirium epidemiology, systems and nursing practice in palliative care inpatient settings: A descriptive mixed methods project (The DePAC Project)

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# Delirium epidemiology, systems and nursing practice in Palliative Care inpatient settings: a descriptive mixed methods project

## (The DePAC Project)

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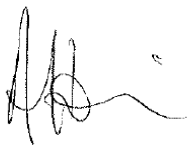
# ***THESIS CERTIFICATION***

I, *Annmarie Hosie*, declare that this Thesis, submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the School of Nursing, The University of Notre Dame Australia, is wholly my own work and contains no material previously published or written by another person, except where due reference is made in the text of the thesis. This document has not been accepted for the award of any other degree or diploma in any university or other institution. Where the work in this thesis is based on co-authored publications, disclosure of the relative contributions of all authors has been made.



March 21, 2016

Tota Tua ego sum, et omnia mea tua sunt. Accipio te in mea omnia. Praebe mihi cor tuum, Maria.

# ***ACKNOWLEDGEMENTS***

There are so many people to thank for the gifts of their support, encouragement and friendship throughout the conception and completion of this PhD that it is difficult to acknowledge each person on this page. I will do my best.

The right place to begin is with my wonderful family. My deep thanks for my husband Richard and his amazing patience and acceptance, and for our children, Charlie, Connor and Evie, who have each good-humouredly sacrificed many things while I undertook this work. Thank you especially, my dear family, for our daily evening meals that sustained me throughout this full time. My thanks also for the abiding love of my parents, Katherine and Mick, sister Kate, and brothers Bernard and Matthew.

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At the beginning my supervisor Jane advised me that a PhD was a journey into the unexpected, and she was right. While this work led me knowingly into a deeper understanding of delirium, palliative care, nursing and research, the unexpected and best understanding that came during this time is that I am Catholic and part of the body of the Church. My everlasting thanks are for Professor Wes Ely who, from the time of a delirium conference in Belgium, invited and then guided me safely back onto the path of the right journey, which is the one walked in love with Jesus Christ. It is He who explains this work, and who lights the way forward.

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# ***ABSTRACT***

## Background

Delirium is a distressing and serious acute neurocognitive disorder frequently experienced by hospitalised patients yet under-recognised by nurses.

## Aim

To identify the actions required to improve the capabilities of specialist inpatient palliative care nurses to recognise and assess delirium.

## Design

A two-phase sequential transformative mixed methods project, involving five studies and underpinned by a knowledge translation conceptual framework – collectively termed the DePAC project.

## Methods

A mixed methods design was used to examine delirium in palliative care inpatient settings from epidemiological, systems and nursing practice perspectives. Participants were nurses, physicians, allied health professionals, managers and patients of Australian palliative care inpatient services. Phase one focused on scoping the problem of delirium in palliative care and included a systematic review on delirium prevalence and incidence, cross sectional study and environmental scan. During Phase two, the Critical Incident Technique and focus groups were used to explore palliative nurses' delirium experiences, perceptions and capabilities. Data from each phase were integrated at the conclusion of the project.

## Results

Palliative care inpatients are a geriatric population at risk of delirium. Internationally, delirium prevalence in palliative care inpatient units ranged from 26% to 62% during admission, increasing up to 88% in the last hours of life. In the cross-sectional study, one in five (19%) palliative care inpatients were diagnosed as delirious in a 24-hour period. Almost all evidence-based guidelines for delirium exclude evidence and recommendations directly acknowledging the care needs of patients who are approaching the end of their life. Strategies for recognising and assessing delirium are missing from palliative care unit systems. Ambiguous terminology and nurses' poor conceptual understanding of delirium contributes to

under-recognition and inadequate assessment. The Nursing Delirium Screening Scale is brief, simple and feasible for use, yet optimal delirium recognition and assessment by nurses also requires rapport with patients, engagement of family, validation of delirium tools in this setting, point-of-care guidance, education relevant to palliative care contexts and interdisciplinary teamwork.

## Conclusion

More careful navigation of palliative care patients away from an incipient or existing episode of delirium is entirely possible and must become core business within specialist palliative care inpatient units. Building the capacity of palliative care nurses to provide exemplary delirium care will be achieved by transforming the DePAC recommendations into concrete action.

# ***RECOMMENDATIONS***

That specialist inpatient palliative care units promote optimal cognitive and physical function for all patients.

That palliative care patients and their family be routinely informed about delirium and supported during and after an episode.

That all Australian specialist inpatient palliative care teams use delirium diagnostic criteria and validated delirium tools to confirm and communicate observations of patients' neurocognitive changes.

That the Palliative Care Outcomes Collaborative tools be expanded to include validated delirium measures.

That the assessment of delirious palliative care patients is routine, comprehensive, structured and person-centred.

That palliative care inpatient services adopt systems to ensure that the informed consent of patients or their family is obtained prior to nurse administration of psychoactive medication.

That the Nu-DESC, 4AT, SQiD, RADAR, and brief and/or family versions of the CAM be validated for use in inpatient palliative care populations.

That a suite of palliative care interdisciplinary delirium education resources be developed.

That interdisciplinary clinical interventions to improve delirium outcomes for palliative care patients and families be developed and tested.

That all future Australian delirium clinical practice guidelines and standards address the needs of palliative care populations in accordance with the best evidence.

# ***ANTHOLOGY OF PUBLICATIONS***

## Published

**Hosie, A**., Lobb, E., Agar, M., Davidson, P. M., Chye, R., & Phillips, J. (2015). Nurse perceptions of the Nursing Delirium Screening Scale in two palliative care inpatient units: a focus group study. *Journal of Clinical Nursing*, n/a-n/a. doi: 10.1111/jocn.12925;

**Hosie, A.** and Phillips, J, Editorial: Nurses' role in improving interdisciplinary delirium care in inpatient settings: steps for action, *Journal of Clinical Nursing*, 2014, **23**(21-22): p. 2995-2997;

**Hosie A.** Developing delirium recognition and assessment in palliative care: an update on The DePAC Project. *Annals of Delirium* 2014; **14**: 2-6; http://www.europeandeliriumassociation.com/silo/files/annals-of-delirium-volume-14-oct-2014.pdf;

Bush, S.H., Leonard, M.M., Agar, M.R., Spiller, J.A., **Hosie, A.**, Wright, D., Meagher, D.J., Currow, D.C., Bruera, E., Lawlor, P.G., End-of-life delirium: issues regarding recognition, optimal management and the role of sedation in the dying phase, *Journal of Pain and Symptom Management*, 2014 Aug; **48**(2): 215-30, doi: 10.1016/j.jpainsymman.2014.05.009;

Lawlor, P., Davis, D., Ansari, M. **Hosie, A**., Kanji, S. Momoli, F. Bush, S. H. Watanabe, S. Currow, D.C. Gagnon, B. Agar, M. Bruera, E. Meagher, D.J. de Rooij, S.E. Adamis, D. Caraceni, A. Marchington, K. & Stewart, D.J., An Analytic Framework for Delirium Research in Palliative Care Settings: Integrated Epidemiological, Clinician-Researcher and Knowledge User Perspectives. *Journal of Pain and Symptom Management*, 2014 **48**(2); 159-75, http://dx.doi.org/10.1016/j.jpainsymman.2013.12.245;

**Hosie, A.,** Agar, M., Lobb, E., Davidson, P.M. and Phillips, J., Palliative care nurses' recognition and assessment of patients with delirium symptoms: A qualitative study using critical incident technique. *International Journal of Nursing Studies* 2014; 51: 1353-65; http://dx.doi.org/10.1016/j.ijnurstu.2014.02.005;

**Hosie, A.,** Agar, M., Lobb, E., Davidson, P.M. and Phillips, J., Identifying the barriers and enablers to palliative care nurses' recognition and assessment of delirium symptoms: a qualitative study, *Journal of Pain and Symptom Management*, 2014, doi: 10.1016/j.jpainsymman.2014.01.008;

**Hosie, A.,** Davidson, P.M., Agar, M., Sanderson, C.R. and Phillips, J. Delirium prevalence, incidence, and implications for screening in specialist palliative care inpatient settings: A systematic review. *Palliative Medicine*, 2013, 27, 486-498.

## Invited Presentations

**Hosie, A.** (2014) 'Delirium assessment and management in palliative and aged contexts', Management of Symptoms in Advanced Illness Workshop, Sacred Heart Health Service and the Cunningham Centre for Palliative Care, Darlinghurst, NSW, Australia;

**Hosie, A.** (2014) 'Delirium assessment and management in the aged care and palliative care context', with Ms Claudia Virdun and Dr Louise Hickman (Unit coordinators), 3-hour workshop for 3rd year nursing students, The University of Technology, Sydney, NSW, Australia;

**Hosie, A.** (2014) 'Delirium: Implications for cancer care', Addressing the geriatric needs of older people with cancer: nurse led strategies, CNSA Pre-conference Workshop, Clinical Oncology Society of Australia, Melbourne, Victoria, Australia;

**Hosie, A.** (2014) Building the evidence-base of delirium in palliative care: from pathophysiology to implementation, with: Agar, M, Phillips, J and Davidson, P, School of Nursing, Johns Hopkins University, Baltimore, US;

**Hosie, A.,** Phillips, J., Agar, M., Weckmann, M., Lawlor, P. and Bush, S., (2014) **'**Interdisciplinary management of delirium in palliative care: collaboratively building the evidence base', 2-hour workshop on palliative care and delirium, 4th Annual American Delirium Society Meeting, June 1-3, 2014, Baltimore, US;

**Hosie, A.** (2014) **'**Delirium and nursing practice', 30-minute podcast recorded for 3rd year nursing students, The University of Notre Dame Australia, Darlinghurst, NSW, Australia;

**Hosie, A.** and Agar, M (2014) **'**Recognising, assessing and managing delirium in palliative care', 90-minute workshop at the Palliative Care Nurses Australia 5th Biennial Conference, Sydney;

**Hosie, A.** (2013) 'Delirium Assessment and Management in Palliative and Aged Care Contexts', with Ms Claudia Virdun and Dr Louise Hickman (Unit coordinators), 3-hour workshop for 3rd year nursing student, The University of Technology, Sydney.

## Peer Reviewed Conference (Oral) Presentations

**Hosie, A**, Davidson, P.M., Agar, M., Lobb, E. and Phillips, J, (2014) 'Nurse perceptions of barriers and enablers to recognition and assessment of palliative care inpatients' symptoms of delirium: a qualitative study', Delirium Clinical and Research Day (DECLARED), Melbourne, Victoria, Australia;

**Hosie, A,** Davidson, P.M., Agar, M., Lobb, E. and Phillips, J, (2014) 'Barriers and enablers to palliative care nurse recognition and assessment of inpatients' delirium symptoms: a qualitative study', PCNA Conference, Sydney, NSW, Australia;

**Hosie, A.**, Davidson, P.M., Agar, M., Lobb, E. and Phillips, J., (2013) 'Exploring recognition and assessment of delirium symptoms by palliative care nurses: a qualitative study', 12th Australian Palliative Care Conference, Canberra, ACT, Australia;

**Hosie, A.**, Davidson, P.M., Agar, M., Sanderson, C.R. and Phillips, J, (2012)'A systematic review of the prevalence and incidence of delirium in specialist palliative care inpatient units, European Delirium Association 7th Annual Meeting, Bielefeld, Germany,

## Peer Reviewed Conference (Poster) Presentations

**Hosie, A.**, Davidson, P.M., Agar, M., Lobb, E. and Phillips, J., (2014) 'Palliative Care Nurse Perceptions of Barriers and Enablers to Recognition and Assessment of Patients' Delirium Symptoms: A Qualitative Study', 4th Annual Meeting of the American Delirium Society, Baltimore, MA, United States;

**Hosie, A.**, Davidson, P.M., Agar, M., Lobb, E. and Phillips, J., 'Exploring recognition and assessment of delirium symptoms by palliative care nurses using the Critical Incident Technique', European Delirium Association 8th Annual Meeting, 2013, Leuven, Belgium;

**Hosie, A,** Davidson, P.M., Agar, M., Sanderson, C.R. and Phillips, J., 'Does the prevalence and incidence of delirium in specialist inpatient palliative care units necessitate routine delirium screening? A pictorial exposition of the evidence.' NSW State Palliative Care Conference: "Reaching Out: Community, Communicating, Connecting, Dubbo, (Awarded 2nd prize).

## Other presentations

**Hosie, A**. (2014) The DePAC Study: Delirium Prevalence, Systems and Nursing Practice in Palliative Care (Overview), ImPaCCT and the Centre for Cardiovascular and Chronic Care (CCCC), Palliative Care Research Concept Development Workshop, University of Technology Sydney;

**Hosie, A**. (2014) Delirium prevalence, systems and nursing practice in palliative care settings: The DePAC Study, Progress report, Summer School, CCCC, University of Technology Sydney;

**Hosie, A.** (2013) Palliative care nurses' recognition and assessment of delirium symptoms: a qualitative study, Palliative care seminar, Sacred Heart Health Service and the Cunningham Centre for Palliative Care, Darlinghurst;

**Hosie, A.** (2013) Palliative care nurses' recognition and assessment of delirium symptoms: a qualitative study, Braeside Palliative Care Service, Prairievale;

**Hosie, A.** (2013) Delirium recognition and assessment in palliative care inpatient settings, St Joseph's Palliative Care Unit, Auburn, NSW.

## Media presentations

1. **Hosie, A**. 2013. *Palliative care research* [Online]. NSW Nurses and Midwives' Association. Available: http://www.nurseuncut.com.au/palliative-care-research
2. Nurses for Nurses, Webinar presentation, 2013, Delirium Prevalence and Incidence in Palliative Care Inpatient Settings: Implications for Nurse Recognition and Assessment of Delirium: http://www.nursesfornurses.com.au/hse-public.aspx
3. The Sydney Morning Herald, 2012, *Debunking the normalcy of delirium:* http://newsstore.fairfax.com.au/apps/viewDocument.ac?page=1&sy=afr&kw=Notre+Dame&pb=all_ffx&dt=selectRange&dr=1year&so=relevance&sf=text&sf=headline&rc=10&rm=200&sp=nrm&clsPage=1&docID=SMH121220BR2LE7H18JV
4. Catholic Communications, 2012, *Notre Dame Doctoral Student Makes Important Contribution to Palliative Care*, from https://http://www.sydneycatholic.org/news/latest_news/2012/20121218_1100.shtml
5. Nursing Careers Allied Health: http://www.ncah.com.au/news -events/nurse-aims-to-improve-quality-of-life-for-palliative-care-patients/1605/
6. The University of Notre Dame Australia, 2012, *Research may improve quality of life for palliative care patients with delirium*: http://www.nd.edu.au/news/media-releases/2012/135
7. Caresearch, *Nurses in the spotlight*: http://www.caresearch.com.au/Caresearch/Portals/0/Documents/PROFESSIONAL-GROUPS/Nurses%20Hub/NH_NurseSpotlight_Hosie_July2011.pdf

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# ***ABBREVIATIONS***

| | |
|---|---|
| ACSQHC | Australian Commission on Safety and Quality in Health Care |
| AIN | Assistant in Nursing |
| AKPS | Australian-modified Karnofsky Performance Score |
| APA | American Psychiatric Association |
| CIHR | Canadian Institutes for Health Research |
| CIT | Critical Incident Technique |
| CNC | Clinical nurse consultant |
| CNS | Clinical Nurse Specialist |
| DSM | Diagnostic and Statistical Manual of Mental Disorders |
| EN | Enrolled Nurse |
| HIV/AIDS | Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome |
| HREC | Human Research Ethics Committee |
| KPI | Key Performance Indicator |
| KT | Knowledge Translation |
| KTA | Knowledge to Action |
| MDT | Multidisciplinary Team |
| NA | Not Applicable |
| NHMRC | Australian Government National Health and Medical Research Council |
| NSW | New South Wales |
| NUM | Nursing Unit Manager |
| PCOC | Palliative Care Clinical Outcomes Collaborative |
| QI | Quality Improvement |
| QOL | Quality Of Life |
| RN | Registered Nurse |
| SPSS | Statistical Package for the Social Sciences |
| UK | United Kingdom |
| US | United States |
| VIC | Victoria |
| WA | Western Australia |
| WHO | World Health Organisation |

# ***GLOSSARY***

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| Advanced Practice Nursing | Level of nursing practice that requires a high degree of knowledge, skill and experience to be applied in the nurse-patient relationship. Involves critical analysis, problem solving and accurate decision-making. Nurses practising at this level are expected to (or be working towards) a Masters level degree (Nursing and Midwifery Board of Australia, 2015). Includes Clinical Nurse Specialists, Clinical Nurse Consultants, Clinical Nurse Educators and Nurse Practitioners. |
| Assessment | An evidence-based, comprehensive, systematic and structured process that applies knowledge, incorporates patient data from a variety of sources, considers the patient holistically, is conducted sensitively and supportively and confirms findings with the patient and health care team (Nursing and Midwifery Board of Australia, 2006) Comprehensive assessment of the patient is a core responsibility of the registered nurse (Nursing and Midwifery Board of Australia, 2006). |
| Assistant in Nursing | Unlicensed worker with the equivalent of 12 months basic nursing training, who is delegated by their employer and the registered nurse to provide basic patient care (NSW Department of Health, 2009). |
| Australian-modified Karnofsky Performance Score | Validated measure of a patient's overall performance status, using 10-point increments along a scale of 100-10 (100 denotes normal function with no evidence of disease, while minimum score of 10 denotes the patient is comatose or barely rousable) (Abernethy, Shelby-James, Fazekas, Woods, & Currow, 2005). |
| Clinical practice | Professional activities undertaken by health care practitioners for the purposes of investigating patient symptoms and preventing and/or managing illness (Australian Council for Safety and Quality in Health Care, 2005). |
| Clinical Practice Guidelines | Systematically derived recommendations based on the best available scientific evidence, that are developed to guide health care professionals and patients to make decisions according to the most effective, safe and efficient interventions for a specific health-related problem (World Health Organisation, 2015). |
| Clinician | A medical, nursing or allied health professional who directly provides patient care. |
| Cognitive impairment | An inability to remember, recall and problem solve (NSW Agency for Clinical Innovation, 2014). |

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| Critical Incident Technique | Research method with a defined set of procedures for collecting direct observations of human behavior, to determine their potential usefulness in solving practical problems and developing broad psychological principles. The method outlines processes to collect observed incidents that have special significance and meet systematically defined criteria (Flanagan, 1954). |
| Cross sectional study | Study measuring the frequency and characteristics of a disease, syndrome or health status of a population at one point in time. Also termed 'point-prevalence' study (Bonita, Beaglehole, & Kjellstrom, 2006). |
| Decision aids | Tools that help people become involved in decision making by clarifying what needs to be decided, providing information about options and outcomes, and by identifying personal values. Decision aids are designed to complement information and guidance given by a health care professional (Patient Decision Aids, 2015) |
| Delirium | Neurocognitive disorder, characterised by acute disturbance to attention, awareness and cognition arising from physiological causes (American Psychiatric Association, 2013). |
| Delirium assessment tools | Predominantly measure the severity and/or phenomenological characteristics of a patient's experience of delirium or cognitive impairment (Adamis, Sharma, Whelan, & MacDonald, 2010). They may also be used to determine a differential diagnosis and monitor the patient's response to intervention (Woodford & George, 2007). |
| Delirium confirmation | Clinical determination that a patient has delirium based upon a validated tool. Delirium confirmation tools are usually dichotomous in nature, providing either a 'yes/no' result or alternatively, a cutoff score that has been validated against the 'gold standard' of a psychiatrist applying diagnostic criteria (Adamis, et al., 2010; Neufeld et al., 2014). Medical, nursing or allied health professionals who have received adequate training in their use can administer these tools to confirm the presence of delirium (Australian Commission on Safety and Quality in Health Care, 2014). |
| Delirium diagnosis | A medical determination that a patient has delirium based upon diagnostic criteria. The most commonly used diagnostic criteria for delirium is that provided by the American Psychiatric Association Diagnostic and Statistical Manual (American Psychiatric Association, 2013). |

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| Dementia | Range of diseases characterised by decline in the person's cognition and variously impacting upon complex attention, executive function, language, memory, learning, perception, motor skills, personality, and the ability to undertake the activities of daily living. Categorised in the DSM-5 as: 'major and mild neurocognitive disorders' (American Psychiatric Association, 2013). |
| Diagnostic Criteria | Framework of signs, symptoms, history, and/or test results that together determine if a condition is present (Bonita, et al., 2006). |
| Dying | The last days, hours or minutes of life, where it is clear the person is passing from life. Physical signs of dying include changes to breathing patterns, slowing of circulation, reduced oral intake, urine output and consciousness. Synonymous with 'terminal stage/phase'. |
| End of life | Period of time when a person is living with an advanced, progressive life-limiting illness (ACI Palliative Care Network 2013). |
| End of life care | Care of people during the end of life, provided by a variety of health professionals and carers and across a range of settings (ACI Palliative Care Network 2013). |
| Enrolled nurse | Nurse who has undertaken a 12-month training program resulting in a Certificate IV or Diploma from a vocational education and training provider or equivalent from a recognised hospital-based program, who is licenced to practice on a state or territory nursing and midwifery registration board. Provides nursing care under the supervision of a Registered Nurse (Australian Institute of Health and Welfare, 2015). |
| Environmental Scan | An investigative research process that may use multiple methods to collect external and internal information, so that an organisation can identify resources to assist future development endeavours (Legare et al., 2010). |
| Evidence-based practice | Approach to clinical practice that incorporates the best available evidence, clinician experience and the individual patient's circumstances and preferences (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). |
| Frailty | State of a person, who is usually elderly, having increased vulnerability to poor return to homoeostasis after stress. Frailty increases the risk of further adverse outcomes, including falls, delirium and disability (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013). |
| | All activities designed to promote, restore and/or |

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| Health care system | maintain health; and the people, institutions and resources, arranged together in accordance with established policies, to improve the health of the population they serve (World Health Organisation, 2015). |
| Hyperactive delirium | Delirium subtype where the patient has an increased level of psychomotor activity. There may also be lability of mood, agitation and resistance to medical care (American Psychiatric Association, 2013). |
| Hypoactive delirium | Delirium subtype where the patient has a decreased level of psychomotor activity, along a continuum from lethargy to stupor (American Psychiatric Association, 2013). |
| Iatrogenic | Unintended outcomes caused by a health care intervention. |
| Incidence | Number/rate of new cases of a disease or health condition in a given period of time within a defined population (Bonita, et al., 2006). |
| Interdisciplinary team | Coordinated and coherent connections between different health care disciplines to generate common methods, knowledge and perspectives in patient care. Interactions are centred around the needs of the patient and their family, who involved in discussions and decision-making (Jessup, 2007; Newhouse & Spring, 2010). |
| Key informant | Individual who can provide rich insights and in-depth information about a given topic, situation or environment to the qualitative researcher (Liamputtong, 2013). |
| Key Performance Indicator | Measures of performance according to defined targets or expectations. |
| Knowledge | That derived from scientific research (Graham et al., 2006). |
| Knowledge tools | Dissemination resources that provide evidence in a simplified format for the purpose of implementing knowledge into action; sometimes termed ‘third generation’ knowledge (Brouwers, Stacey, & O’Connor, 2010). Within the DePAC project, delirium knowledge tools are: clinical practice guidelines, delirium and cognition screening, assessment and diagnostic tools, pathways, and clinician or patient decision aids. |
| Knowledge Translation | Systematic process incorporating synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products, and strengthen the health care system (Straus, Tetroe, & Graham, 2009). |

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| Meta-inference | The development of theoretical understanding of a researched area from the integration of the results and findings of mixed methods research with the original 'inference' or theoretical position (Cameron, 2009). |
| Mixed delirium | Delirium subtype where the patient has either a normal or fluctuating level of psychomotor activity (American Psychiatric Association, 2013). |
| Mixed methods research | Mixed methods research uses and integrates quantitative and qualitative methods, either within a single study or a multi-study research project, so that the understanding gained is greater than the sum of its parts (Creswell, 2009). |
| Morbidity | Non-fatal event. |
| Mortality | Fatal event/death. |
| Multidisciplinary | An approach to care of the patient that uses the skills, knowledge and experience of different disciplines. A multidisciplinary team meets regularly to discuss and plan patient care, but care is delivered individually and often from the perspective of the discipline (Jessup, 2007). |
| Older person/people | In the non-Aboriginal and Torres Strait Islander Australian population, people aged 65 years and over; in the Aboriginal and Torres Strait Islander Australian population, people aged 45 years and over (Clinical Epidemiology and Health Service Evaluation Unit Melbourne Health, 2006). |
| Palliative Care | Approach to care that "improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organisation, 2002). |
| Palliative care phase | Phase classification widely used within Australian palliative care services, to describe the needs of the patient and their family and prompt timely and appropriate responses by the team. The phases include: stable, unstable, deteriorating, terminal, bereavement (Eagar, Green, & Gordon, 2004). |
| Paradigm | Philosophical approach or conceptual model that incorporates researchers' shared beliefs and perspectives of the world, reality, the nature of knowledge, methodology and solutions to problems (Creswell, 2011). |
| | Health care of the patient that achieves "…respect, emotional support, physical comfort, information and |

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| Patient-centred care | communication, continuity and transition, care coordination, involvement of family and carers, and access to care" (Australian Commission on Quality and Safety of Healthcare, 2010, p.7). |
| Point-of-care guidance | Paper or electronic resources used at the patients' bedside that provide summarised medical information for use by clinicians (Ketchum, Saleh, & Jeong, 2011). |
| Policy | Formal agreement or consensus that are developed, adopted and/or pursued by a government or organisation to promote actions towards a desired goal. |
| Pragmatism | Paradigm that discounts notions of 'truth' or 'reality' to instead focus on 'what works' practically in regards to the answering of a research question. A philosophical approach to research that includes multiple viewpoints and acknowledges that the values of the researcher are influential in the interpretation of results (Tashakkori, 2003). |
| Prevalence | Number/rate of existing cases of a disease or health condition in a given period of time within a defined population (Bonita, et al., 2006). |
| Prodromal delirium | Manifestation of symptoms such as changes to concentration, mood (irritability, anxiety, depression), sleep patterns (including vivid dreaming), cognition (e.g. disorientation), tiredness or noise sensitivity, that can occur in the hours, days or weeks prior to full syndromal delirium (Gupta, de Jonghe, Schieveld, Leonard, & Meagher, 2008). |
| Protocol | Established set of rules used for the completion of tasks or a set of tasks. (Australian Commission on Safety and Quality in Health Care (ACSQHC), September 2011). |
| Quality Improvement | Continuous, systematic approach to improvement and evaluation of organisational operations to ensure best care of patients (Australian Government, 2012). |
| Recognition of delirium | Rapid realisation by a clinician that a patient who has disturbances to their attention, awareness and cognition may be experiencing delirium, warranting immediate action including comprehensive assessment. |
| Registered Nurse | Nurse or midwife with a minimum of a relevant three year degree from a higher education institution (or previously from a recognised hospital-based program) who is licensed to practice as a nurse or midwife on a state or territory nursing and midwifery board or council (Australian Institute of Health and Welfare, 2015). |

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| Resource Utilisation Groups - Activities of Daily Living (RUG-ADL) | Validated functional assessment tool which assigns a score of 4-18, based on what a patient does, rather than they can do, in relation to bed mobility, transfers, eating and toileting. Higher scores indicate that the patient needs more assistance to undertake these activities and that more resources are required to provide this assistance (Eagar, et al., 2004; Fries et al., 1994). |
| Screening | Application of a test, examination or other rapidly applied procedure for the probable identification of a disease or health condition. Screening is not intended to be diagnostic, but supports the diagnostic process (Wilson & Jungner, 1968). Delirium screening tools support earlier detection of delirium (Gaudreau, Gagnon, Harel, & Roy, 2005). |
| Sequential transformative design | Multi-phase, mixed methods research project with an overarching theoretical perspective that guides the direction of the research and endeavours to ultimately bring about change (Creswell, 2009). |
| Specialist palliative care service | Multi-disciplinary health care service whose substantive work is with patients who have complex needs associated with life limiting illness. Specialist palliative care health professionals are expected to have qualifications or accreditation in palliative care (Palliative Care Australia, 2005). |
| Subsyndromal delirium | Presence of one or more symptoms of delirium, where the patient does not meet the criteria for delirium (Cole, Ciampi, Belzile, & Dubuc-Sarrasin, 2013). Termed ‘attenuated delirium syndrome’ by the DSM-5 (American Psychiatric Association, 2013). |
| Systems | Decision-making, informational, administrative, human resource and clinical processes within a hospital that manage, co-ordinate and support the delivery of patient care (Reid, Compton, Grossman, & Fanjiang, 2005). |
| Terminal condition | Progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. |
| Terminal stage/phase | The last days to hours of life (Eagar, et al., 2004). |

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# Chapter 1: Introduction to the DePAC Project

## 1.1 Introduction

Delirium is an acute neurocognitive disorder that is commonly experienced by hospitalised patients (American Psychiatric Association, 2013; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010). Despite its prevalence, delirium is under-recognised by all disciplines of clinicians, including nurses (Steis & Fick, 2008). Fortunately, growing awareness of the seriousness of delirium for inpatient populations is shaping efforts to improve delirium care and outcomes both nationally (Australian Commission on Quality and Safety of Healthcare, 2015) and internationally (Barr et al., 2013; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010).

Inpatients affected by delirium tend to be older, have advanced or serious illness, and/or prior cognitive impairment (National Clinical Guideline Centre for Acute and Chronic Conditions, 2010). Many patients receiving inpatient palliative care have these characteristics, placing them at increased risk of delirium during their hospital admission.

The *Delirium in Palliative Care Project* ('DePAC project') sought to confirm the occurrence of delirium in specialist palliative care inpatient units and determine the action required to ensure that palliative care inpatients who develop this acute disorder are rapidly identified, impeccably assessed and effectively managed. This mixed method doctoral research project encompassed investigation of delirium epidemiology and exploration of recognition and assessment systems and nursing practice within the Australian specialist inpatient palliative care setting.

This introductory chapter describes the impetus for the DePAC project and outlines the content, structure and key concepts of the thesis.

## 1.2 Impetus for the DePAC project

Delirium adversely impacts patients and their families, clinicians and the health care system. Inpatients who develop delirium have more falls, longer hospital stay, are more likely to be discharged to a nursing home, develop long term cognitive impairment and to die (National Clinical Guideline Centre for Acute and Chronic

Conditions, 2010; Salluh et al., 2015). Patients may struggle to communicate their experiences with others during an episode of delirium and often feel very frightened, confused and isolated (O' Malley, Leonard, Meagher, & O' Keeffe, 2008). Their memories of the delirium experience may generate distress and embarrassment long after the acute episode has resolved (Breitbart, Gibson, & Tremblay, 2002; Teodorczuk, Harrison, Laverty, & Cave, 2011).

Delirium also has economic implications for patients, families and the health care system. Admissions for delirious elderly patients cost two and a half times more for than those without delirium (Leslie, Marcantonio, Zhang, Leo-Summers, & Inouye, 2008). The longer term impact of delirium upon cognitive and functional ability often precludes people from returning to their previous employment and older people from effectively managing at home (Salluh, et al., 2015).

Family members experience high levels of distress and loss of the person as they know them, as well as frustration and uncertainty about what to do during the delirium episode (Day & Higgins, 2015). They often perceive that clinicians could have demonstrated greater respect for their relative during a delirium (Namba et al., 2007). For clinicians working in busy clinical environments, identifying and responding appropriately to delirium is challenging. Primarily because they are usually simultaneously trying to understand their delirious patients' perspectives, maintain a safe environment for all, and manage their own busy workloads. This scenario contributes to clinicians, and nurses in particular, experiencing strain and distress (Leventhal et al., 2013; O' Malley, et al., 2008).

An increased international response to the growing understanding of the seriousness of delirium is initiating responses within health care systems across the developed world. Initiatives in the geriatric and intensive care settings have included: testing and implementation of multicomponent interventions to reduce the incidence, severity, duration and negative outcomes of a delirium episode (Brummel, Girard, et al., 2013; Brummel, Vasilevskis, et al., 2013; Hshieh et al., 2015); and development of clinical practice guidelines (Canadian Coalition for Seniors' Mental Health, 2010; Clinical Epidemiology and Health Service Evaluation Unit Melbourne Health, 2006; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010). While in Australia, an important recent health care initiative is the development of a

delirium clinical care standard for the hospital setting (Australian Commission on Quality and Safety of Healthcare, 2015).

Occurring simultaneously with this broader program of work to minimise the adverse impacts of delirium is a growing awareness of the need to build the delirium evidence and practice in palliative care. The impetus is reflected in a recent call to the international community for further investigation of delirium epidemiology, prevention, recognition, assessment, management and supportive care in palliative care populations and settings (Lawlor et al., 2014).

In clinical practice, delirium under-recognition requires strategies that promote more timely identification (Barnes, Kite, & Kumar, 2010; Fang et al., 2008; Irwin et al., 2008). Early recognition of delirium by the specialist palliative care team is vital for several reasons. Firstly, up to one half of all delirious palliative patients have reversible causes (i.e. infection or medication) (Lawlor et al., 2000). Secondly, early recognition ensures that the patient and family are fully informed, reassured and supported during a delirium episode (Brajtman, 2005; Morita et al., 2007). Identifying palliative care inpatients who are experiencing acute neurocognitive disturbance is also essential so that the potential benefits and burdens of investigation and treatment can be carefully considered alongside the patient's prognosis, wishes and goals of care. This approach ensures that the clinical management of delirium is appropriately tailored for each patient across their illness trajectory (Lawlor & Bush, 2014). Yet undertaking a comprehensive delirium assessment is difficult if the patient is frail, fatigued, breathless and/or unable to communicate verbally, which becomes increasingly likely as death nears (Leonard et al., 2014). In instances where the patient is not able to communicate their wishes, inclusion of their family in the assessment and decision-making is an important component of ethical end of life care (NSW Health, 2005). In the last days and hours of life preventing, reversing and/or ameliorating the symptoms of delirium supports the patient to remain more aware of their family and others and give their last words and gestures of love and acknowledgement (Wright, Brajtman, & Macdonald, 2014).

While in some care settings nurses' contributions to interdisciplinary delirium care are resulting in better patient outcomes (Adams et al., 2015; Hshieh, et al., 2015; Milisen, Lemiengre, Braes, & Foreman, 2005; Naughton et al., 2005), optimal delirium care is hampered if nurses have inadequate delirium knowledge (van de

Steeg, Ijkema, Wagner, & Langelaan, 2015) and/or poor delirium recognition and assessment skills (Rice et al., 2011; Steis & Fick, 2008; Voyer et al., 2012). An absence of organisational policy to guide nursing practice (Flagg, Cox, McDowell, Mwose, & Buelow, 2010; Watson, Brand, & LoGiudice, 2009) and prevailing beliefs that cognitive and functional decline or vulnerability is normal in older patients (Mc Carthy, 2003) also contribute to sub-optimal recognition and management of delirium in inpatient settings.

Delirium prevalence in palliative care populations has been variously reported in the literature (Hjermstad, Loge, & Kaasa, 2004; Le Grand, 2012; Leonard, Agar, Mason, & Lawlor, 2008). However, no reviews have examined the methodological quality and processes of delirium epidemiological studies in palliative care inpatient populations in detail. The relationship between delirium epidemiology, systems for delirium care within specialist palliative inpatient units, or palliative care nurses' capabilities in recognising and assessing this complex neurocognitive disorder is yet to be examined. While delirium evidence-practice gaps have been reported in palliative care inpatient settings, there is insufficient data informing of the exact nature and causes of these gaps and consequently how delirious palliative care patients' needs could be better met, particularly with respect to nursing care (Agar & Lawlor, 2008; Leonard, et al., 2008). The opportunity to improve delirium outcomes for palliative care inpatients by enhancing nursing care was the impetus for the DePAC project.

## 1.3 Aim

The DePAC project aimed to identify the actions required to improve the capabilities of specialist inpatient palliative care nurses to recognise and assess delirium.

## 1.4 Research questions

1. What is the epidemiology of delirium in the palliative care inpatient population?
2. Is delirium recognition and assessment guidance available to nurses working in palliative care inpatient settings?
3. What are specialist palliative care nurses' experiences, perceptions and capabilities in delirium recognition and assessment?

4. What are the barriers and enablers to nurses recognising and assessing delirium in palliative care inpatient settings?
5. What is required to improve the capabilities of nurses to recognise and assess delirium in palliative care inpatient settings?

## 1.5 Thesis outline

To answer these questions this doctoral research project adopted a mixed methods research design guided by a knowledge translation conceptual framework. The DePAC project has generated five interrelated studies and four peer-reviewed journal publications. The five studies are presented within this thesis as stand-alone reports, similar to the style of a journal article. Chapters containing the published studies have been edited to minimise repetition and ensure consistency of terminology and a logical flow throughout the thesis.

The structure and content of these eight chapters is presented within the navigational Table 1.1, below:

***Table 1.1 Thesis navigational tool***

| SEQUENCE | CONTENT | CHAPTER |
|---|---|---|
| **Preliminary** | Introduction to the DePAC project | One |
| **Phase 1** | **Scoping the problem** | |
| | Study 1: Systematic Review | Two |
| | Conceptual framework, design and methods | Three |
| | Study 2: Environmental Scan | Four |
| | Study 3: Cross sectional study | Five |
| **Phase 2** | **Exploring palliative nurses' delirium experiences, perceptions and capabilities** | |
| | Study 4: Critical Incident Technique | Six |
| | Study 5: Focus Groups | Seven |
| **Conclusion** | Integration and meta-inference of data, recommendations and conclusions of the DePAC project | Eight |

Appendices include: i) supporting delirium information; ii) copies of publications; iii) data collection tools; iv) Human Research Ethics Committee (HREC) approvals; v) study information and consent documents; and vi) a copy of the Australian and New Zealand Society of Palliative Medicine/Palliative Care Nurses Australia Joint Submission to the Australian Commission for Quality and Safety of Health Care, July 2015.

## 1.6 Key concepts within this thesis

This section outlines delirium phenomenology, diagnostic criteria and the broad components of optimal delirium care in relationship to recognition, assessment, diagnosis, confirmation and management. Specialist inpatient palliative care provision in Australia and the characteristics of the patient population are also described.

### 1.6.1 Delirium

*Phenomenology*

Delirium causes acute disturbance to attention, awareness and cognition, which manifests in a variety of ways (American Psychiatric Association, 2013; Meagher, Adamis, Trzepacz, & Leonard, 2012). Cognitive disturbances include memory deficits, disorientation, language and visuospatial disability, and perceptual disturbances, such as illusions, hallucinations or delusions. Perceptual disturbances are usually very frightening for the patient, and may cause him or her to become suspicious and aggressive towards others, including those caring for them (Breitbart & Alici, 2008). Labile mood and an altered sleep-wake cycle also often occur (Meagher et al., 2011). Delirium symptom intensity ranges from mild to severe; while its duration is hours to days, but sometimes weeks or even months (American Psychiatric Association, 2013).

While delirium is treated as one disorder, there are at least three psychomotor subtypes: i) hyperactive delirium, which presents as increased motor activity, agitation and heightened states of arousal; ii) hypoactive delirium, manifesting as decreased motor activity, delayed response and drowsiness; or iii) mixed delirium, where hyperactive and hypoactive states fluctuate during the 24-hour period (American Psychiatric Association, 2013; Gupta, de Jonghe, Schieveld, Leonard, & Meagher, 2008). Meagher et al (2011) also reported that some palliative care

patients experience 'no subtype', or a varied subtype, across the course of the delirium episode.

Delirium always arises from physiological disturbances related to a medical condition, substance intoxication or withdrawal and/or a toxin (American Psychiatric Association, 2013). When a patient is predisposed to delirium, such as through being of older age or having dementia or advanced illness, any exposure to precipitating factors potentiates the likelihood of developing delirium during a hospital admission (Ahmed, Leurent, & Sampson, 2014). Predisposing and precipitating factors for delirium are numerous and are tabulated in Appendix 1.1. Many commonly administered medications for symptom management in palliative care can become iatrogenic precipitants of delirium (i.e. opioids, benzodiazepines and corticosteroids) (Caraceni, 2013; Clark & Currow, 2015). In palliative care settings, antipsychotics are commonly prescribed for a range of symptoms, including perceptual disturbances in delirium (Crawford et al., 2013). However, a recent study reported that some antipsychotics actually increase the severity of delirium symptoms in this patient population (Agar et al., 2015). Underscoring palliative care patients' heightened risk of an episode, as well as the challenges of assessing and treating delirium in this population, is that they often have up to five or six *causative factors (Meagher, et al., 2011).*

*Diagnostic criteria*

Since delirium was first included within the American Psychiatric Association (APA) Diagnostic and Statistical Manual (DSM) in 1980 there have been five iterations of the delirium diagnostic criteria. These changes reflect an evolving understanding of delirium's core features. Appendix 1.2 provides details of how the APA-DSM criteria have been continuously refined over the past 35 years.

Midway through the DePAC project (2011-2015), the diagnostic criteria for delirium was revised in the DSM-5 (American Psychiatric Association, 2013). The DePAC studies conducted and published prior to 2013 therefore refer to the DSM-IV-TR diagnostic criteria (American Psychiatric Association, 2000), while those conducted and published or written after this time use the DSM-5 (American Psychiatric Association, 2013).

Delirium diagnostic criteria less commonly used in the research literature but referred to at one point within this thesis are the International Statistical Classification of Diseases and Related Health problems (ICD-10) Diagnostic Criteria for Research (World Health Organisation, 1993).

*Broad components of optimal delirium care*

Optimal care of hospitalised patients who are at risk of or experiencing delirium consists of: prevention, routine screening, confirmation, comprehensive assessment and non-pharmacological interventions based upon the individual's needs (Australian Commission on Quality and Safety of Healthcare, 2015). Antipsychotic or sedative medication is currently recommended if the patient is very agitated, experiencing severe perceptual disturbance, at risk to themselves or others, or to carry out necessary investigations or treatments (Australian Commission on Safety and Quality in Health Care, 2013; Canadian Coalition for Seniors' Mental Health, 2010; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010; Palliative Care Expert Group, 2010). This recommendation is likely to be changed in light of the recently reported negative results of a randomised controlled trial (RCT) of antipsychotics for targeted delirium symptoms in this population highlighted above (Agar, et al., 2015). Patients who experience longer-term problems of cognitive impairment as a result of delirium will furthermore often require ongoing rehabilitative and supportive care after discharge home from hospital (Pandharipande et al., 2013).

### 1.6.2 Palliative care in Australia

In Australia palliative care is provided in public and private hospitals, hospices and the community for people of all ages with life limiting illness. Australian governments and palliative care services accept the World Health Organisation definition of palliative care, which is:

> *… an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation, 2002).*

Palliative care nurtures life, views dying as a normal process and intends to neither hasten nor postpone death. A team approach is used to best address the multiple and at times complex needs of people living with advanced illness. Palliative care is compatible with active interventions for disease and investigation of distressing symptoms and clinical complications, if these are required to better manage and understand a patient's condition or problems (World Health Organisation, 2002).

### 1.6.3 Models of service provision

Models of palliative care differ across State and Territory jurisdictions, according to variations in funding, health care systems, geographical and demographic factors, and needs of local populations (Australian Institute of Health and Welfare, 2014). For equity of access to appropriate palliative care, the Australian and State and Territory governments have all endorsed the National Palliative Care Strategy (Palliative Care Australia, 2010). This strategy advocates for primary, societal and specialist approaches to palliative care (Australian Institute of Health and Welfare, 2014), as defined below:

*Primary palliative care* includes symptom management, provision of information and holistic support of patients and families at the end of life by health carers across different settings of care (Palliative Care Australia, 2005b).

*Societal palliative care* highlights the integral role of families, carers, volunteers and community and charitable organisations in caring for people approaching the end of life (Palliative Care Australia, 2010).

*Specialist palliative care*, which is the focus of the DePAC project, refers to a multidisciplinary service whose substantive work is with patients who have complex needs associated with life limiting illness. This approach includes management of complex symptoms and therapeutic intervention for significant emotional distress, conflict and/or medically or ethically challenging end of life decision-making (Palliative Care Australia, 2005b). Ideally, clinicians who work within specialist services are qualified and/or accredited in palliative care (Palliative Care Australia, 2005a).

*Specialist palliative care provision*

Specialist palliative care is provided in most metropolitan hospitals and in the community, for example: in home, residential aged care or group home settings

(Australian Institute of Health and Welfare, 2014). In hospitals, specialist care is directly provided in designated palliative care units or mixed units (e.g. palliative care and oncology or palliative care and rehabilitation); or consultatively, when patients are being cared for in other settings such as geriatric or intensive care units. The DePAC project focused upon *designated palliative care* and *mixed units* situated in acute and sub-acute hospitals within the public health care system.

### 1.6.4 Characteristics of the Australian palliative care inpatient population

*The i*npatient population receiving specialist palliative care in designated units represents 0.6% of the hospital population (Australian Institute of Health and Welfare, 2014). Palliative care inpatients are older (X 72.2 years) and have life limiting illnesses, including: malignancy (57.5%), cardiovascular (7.1%) and/or respiratory disease (6.7%). Almost 40% of palliative care patients were born overseas and 15% prefer to speak a language other than English at home (Allingham, Holloway, & Clapham, 2013).

Patients are admitted for the purposes of symptom management, respite or terminal care (Palliative Care Australia, 2005a). Average length of hospital stay in a palliative care inpatient unit is almost four times longer than the wider hospital population (11.2 vs 3.0 days), and just over half of all palliative care patients' die during their hospital admission (51.5%) (Australian Institute of Health and Welfare, 2014).

## 1.7 Summary

Older people with advanced disease and/or prior cognitive impairment are at risk of delirium during a hospital admission. There is currently great impetus internationally and nationally to improve patients' care and outcomes related to this serious acute disorder. The DePAC project undertook a detailed examination of delirium in palliative care inpatient units at the epidemiological, systems, and nursing practice levels. This research aims to inform future interventions to strengthen the delirium recognition and assessment capabilities of palliative care nurses, with the ultimate goal of improving delirium outcomes for palliative patients receiving care in the hospital setting.

Chapter two reports a systematic review of delirium prevalence and incidence in palliative care inpatient unit populations, which was the first study of the DePAC

project. The study was undertaken to answer the research question: ‘What is the epidemiology of delirium in the palliative care inpatient population?

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# Chapter 2: Delirium epidemiology in palliative care inpatient unit populations

## 2.1 Chapter preface

Chapter one outlined the impetus for the DePAC project and its aim and research questions. An overview of the content, structure and core concepts of the thesis were provided.

Chapter two reports a systematic review of delirium prevalence and incidence in palliative care inpatient unit populations. The systematic review was undertaken to answer the research question: 'What is the epidemiology of delirium in the palliative care inpatient population?'

This study was published in 2013 in *Palliative Medicine,* a peer reviewed scholarly journal that focuses upon research and practice relevant to palliative care of people with advanced disease. The article was aimed at an international clinician and researcher audience. Chapter two contains an edited version of the publication, which is provided in its published form in Appendix 2.

## 2.2 Publication Reference

Hosie, A., Davidson, P. M., Agar, M., Sanderson, C. R. & Phillips, J., Delirium prevalence, incidence, and implications for screening in specialist palliative care inpatient settings: A systematic review. *Palliative Medicine,* 2013. **27**(6): p. 486-498, doi: 10.1177/0269216312457214

## 2.3 Introduction

Use of screening and assessment tools improves clinician recognition of delirium and supports the diagnostic process (Gaudreau, Gagnon, Harel, & Roy, 2005; Wilson & Jungner, 1968), yet these tools are not routinely used in the palliative care inpatient setting (Smith & Adcock, 2012). Evidence of the rate of occurrence of delirium in palliative care populations is required to advocate for routine processes to recognise and assess patients' delirium. Previous reviews of delirium in palliative care settings have provided comprehensive examinations of the literature, including delirium prevalence and assessment methods (Breitbart & Alici, 2008; Hjermstad, Loge, & Kaasa, 2004; Leonard, Agar, Mason, & Lawlor, 2008). However, no reviews examine in detail the methodological quality of delirium epidemiological studies conducted in palliative care inpatient units. Nor has the literature discussed the implications of delirium epidemiology in conjunction with other evidence required to justify and promote implementation of routine delirium detection processes in this setting (Harris, 2001; Wilson & Jungner, 1968).

## 2.4 Aims

The aims of this study were to: i) examine prevalence and incidence of delirium and its subtypes in palliative care inpatient unit populations, at various stages of patients' admission; ii) describe how delirium cases were identified and established in included studies; and iii) discuss results with respect to implementation of routine delirium recognition and assessment processes in palliative care inpatient units.

## 2.5 Method

A systematic review of original studies measuring delirium epidemiology in the palliative care inpatient unit populations was conducted. Although a meta-analysis of data was not undertaken, the Meta-analysis of Observational Studies in Epidemiology (MOOSE) (Stroup et al., 2000) guidelines were followed to facilitate systematic processes in the completion and reporting of the review, where relevant.

### 2.5.1 Search method

This systematic review was undertaken between 1 December 2011 to 29 February 2012 and was limited to studies published since 1980 when delirium was first identified within the DSM-III (American Psychiatric Association, 1980) up until early 2012. Prospective search questions guided the search strategy using the

following search Medical Subject Headings (MeSH) and key words along with their associated derivatives: 'delirium' OR 'confusion' OR 'terminal agitation' OR 'terminal restlessness' OR 'psychomotor agitation' OR 'cognitive failure' OR 'disorientation' AND 'palliative care' OR 'death' OR 'dying' OR 'terminal care' OR 'hospice care' OR 'terminally ill' OR 'end of life' AND 'prevalence' OR 'incidence' OR 'epidemiology'. Search engines used were Scopus, CINAHL and Medline. In addition, the search terms 'delirium' AND prevalence OR incidence OR epidemiology were employed in PubMed using the palliative care filter from CareSearch (Flinders University of South Australia, 2012). Reference lists of included studies (Hjermstad, et al., 2004; Leonard, et al., 2008) were examined to search for other potentially eligible papers.

### 2.5.2 Study selection

Criteria for inclusion of papers were prospective assessment studies reporting prevalence, incidence or rate of occurrence of delirium, conducted within designated palliative care inpatient settings (defined as palliative care inpatient units or hospices) with adult participants. Studies were excluded if they were not published in English or reported the rate of occurrence of symptoms or phenomena that were not specifically categorized as delirium, such as 'cognitive failure', 'confusion' or 'terminal agitation', as the interchangeable use of such terms has previously contributed to a lack of clarity in reporting and collating of delirium occurrence in palliative care populations (Hjermstad, et al., 2004). The researcher and one supervisor (JP) examined the titles and abstracts of all papers to determine if they met the inclusion criteria, the researcher extracted data from potentially relevant studies (n=13) and this guided decision-making about inclusion of studies.

### 2.5.3 Assessment of methodological quality of included studies

The methodological quality of included studies was assessed with reference to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines (von Elm et al., 2007) and criteria developed by Boyle (1998) (Boyle, 1998) to evaluate prevalence studies, as detailed below:

1. Sample:
    - Explanation of how the sample size was determined;
    - Study population clearly defined;

- Two-phase sampling process: delirium screening followed by confirmation;
- Minimum of 80% participation within eligible study population;

2. Measurement:
   - Standardized data collection methods for all participants of the study;
   - Use of valid delirium screening and confirmation tools AND/OR psychiatric assessment;
   - Reporting of measurement reliability processes e.g. user training in the delirium screening and confirmation tool/s, inter-rater reliability testing, supervision of clinical/research staff conducting study measurements;
3. Analysis:
   - Confidence intervals included for statistical analysis of frequency estimates.

## 2.6 Results

The initial search generated 811 papers: Scopus (n= 758), CINAHL (n=28), Medline (n= 8), PubMed via CareSearch (n= 21). Within Scopus, adding 'AND prospective study', further refined the search and reduced the number of results within Scopus to 84 papers, resulting in 141 papers across all search engines. Once duplicates were removed 119 papers published between 1980 and 2011 remained (Figure 2.1). A further 113 papers were removed as they either did not report primary research data or prospectively measure prevalence or incidence rates of delirium in adult palliative care inpatient units, leaving six papers. Two additional papers (Durkin, Kearney, & O'Siorain, 2003; Lam, Tse, & Lee, 2003) were identified from a hand search of the reference lists of the eligible papers and other reviews (Hjermstad, et al., 2004; Leonard, et al., 2008). At the end of the search, eight studies that prospectively measured the prevalence or incidence of delirium in specialist palliative care adult

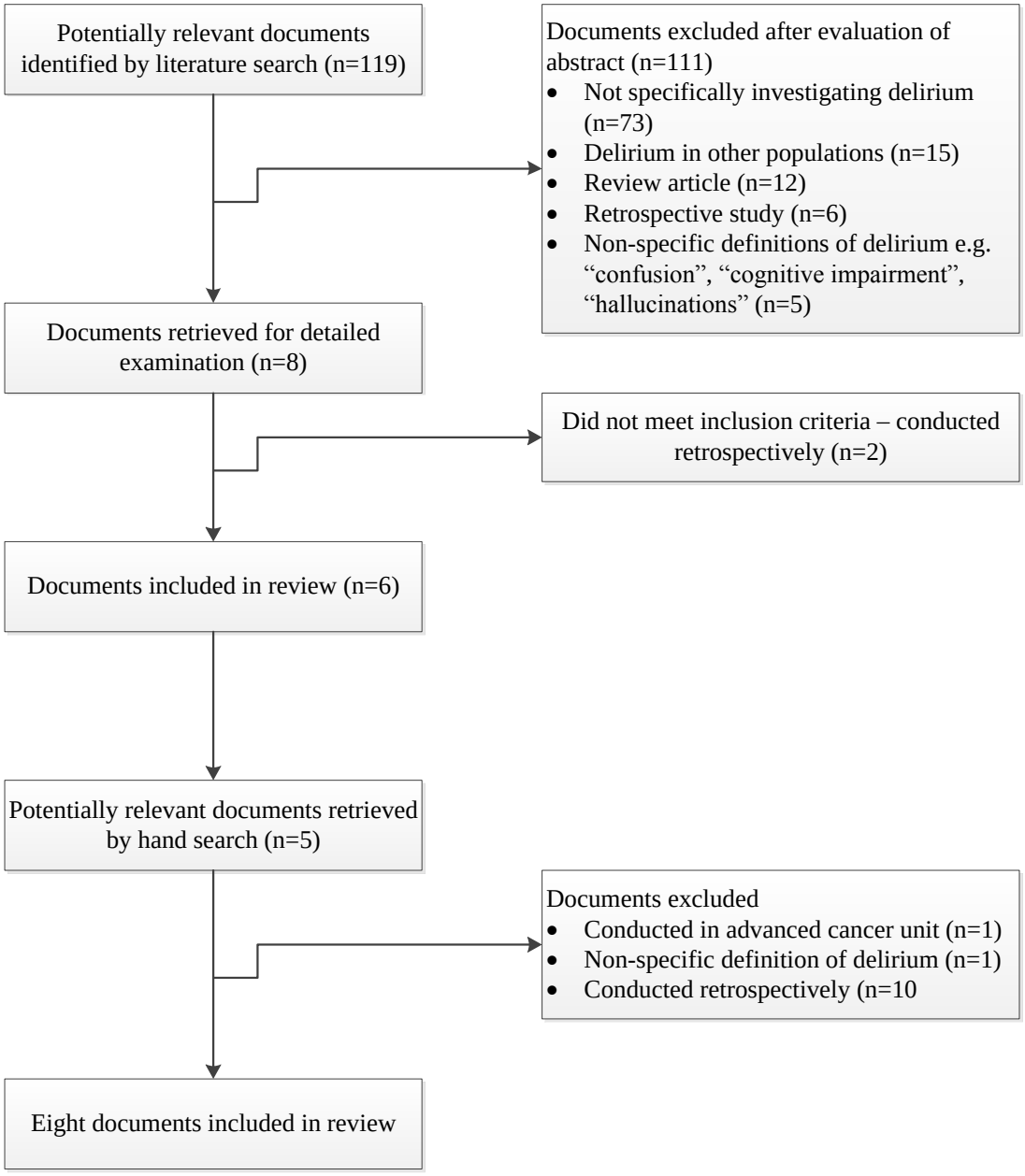


***Figure 2.1 Flow chart of studies from search to inclusion***

inpatient population remained (Table 2.1) (Durkin, et al., 2003; Fang et al., 2008; Gagnon, Allard, Mâsse, & DeSerres, 2000; Lam, et al., 2003; Lawlor, Gagnon, et al., 2000; Minagawa, Uchitomi, Yamawaki, & Ishitani, 1996; Sarhill, Walsh, Nelson, LeGrand, & Davis, 2001; Spiller & Keen, 2006). The included studies were all conducted in the northern hemisphere over a 12-year period (1996-2008).

### 2.6.1 Characteristics of the settings and population

The studies were undertaken in inpatient settings described variously as hospices (n=2) (Gagnon, et al., 2000; Spiller & Keen, 2006), palliative care units (n=3) (Durkin, et al., 2003; Lam, et al., 2003; Minagawa, et al., 1996), acute palliative care units (n=2) (Lawlor, Gagnon, et al., 2000; Sarhill, et al., 2001) and a combined acute palliative care unit/ hospice (n=1) (Fang, et al., 2008). Where described, the purpose of care settings included symptom control, respite, rehabilitation and/or terminal care for palliative care patients. The majority (98.9%) of all participants (n=1079) across these studies had advanced cancer, with some participants' diagnoses not specified in one study (Spiller & Keen, 2006). Two studies included participants with other life limiting diseases: i) immunodeficiency disorders (n=11) (Durkin, et al., 2003); and ii) end-stage cardiac failure and cerebrovascular disease (n=1) (Spiller & Keen, 2006).

Across the studies there was equal representation of males and females, with a mean age of 66.24 years (range 62 to 68.7 years). Participation rates varied. (Table 2.1)

### 2.6.2 Study characteristics, design, quality and foci

There was variability in study characteristics, design, quality and foci, as well as participant numbers (X 120, range 41(Sarhill, et al., 2001) to 228 people (Fang, et al., 2008)). No studies reported statistical explanations for determination of sample size, with this appearing to be largely determined by number of patient admissions within study periods. Delirium occurrence was measured at different frequencies and points of time during the admission, while five studies measured both delirium prevalence and incidence (Durkin, et al., 2003; Gagnon, et al., 2000; Lam, et al., 2003; Lawlor, Gagnon, et al., 2000; Spiller & Keen, 2006).

Different criteria were used to define the terminal stage. In two studies the last weeks of life were considered the "pre-terminal and terminal" stage of cancer (Fang, et al., 2008; Gagnon, et al., 2000). 'Terminally ill' or 'terminal cancer patients' were

elsewhere considered to be within the last six months of life (Minagawa, et al., 1996). Only one study reported data collected in the six hours immediately prior to death, which was termed 'terminal delirium' (Lawlor, Gagnon, et al., 2000).

Methodological quality of studies varied considerably and no study met all quality criteria. (Table 2.1)

### 2.6.3 Definitions of delirium and diagnostic criteria used

Diagnostic criteria adopted by many of the studies that were conducted at different time points reflect the evolution of the DSM for delirium, as referred to in Chapter one and detailed in Appendix 1.2. The majority of studies (n=6) applied DSM criteria to diagnose delirium, with two using the research gold standard of psychiatrist assessment to confirm delirium against the DSM version current at the time (Fang, et al., 2008; Minagawa, et al., 1996). In another four studies diagnosis of delirium was based on the DSM criteria without psychiatrist confirmation (Gagnon, et al., 2000; Lam, et al., 2003; Lawlor, Gagnon, et al., 2000; Spiller & Keen, 2006). The remaining two studies used alternative strategies to establish a delirium diagnosis. Durkin et al (2003) used the ICD-10 Diagnostic Criteria for Research which requires a greater range of symptoms to be present to establish a delirium diagnosis (World Health Organisation, 1993). Sarhill et al used no diagnostic criteria (2001).

***Table 2.1 Features of included studies***

| Publication | Country | Aim | Design/Screening & Assessment Tools/DSM Criteria | Participants/ Participation Rate | Delirium Prevalence/ Incidence Results | Quality Considerations |
|---|---|---|---|---|---|---|
| Minagawa et al, (1996) | Japan | Demonstrate range of psychiatric disorders in a PC unit. | Prospective assessment by psychiatric investigator using MMSE, psychiatric assessment and SCID within 1 week of admission.<br>DSM-III-R | Terminally ill cancer inpatients (n=93); 59% male; mean age 67.2 SD ± 11.9 years; participation rate 85%. | 53.7% met DSM-III-R criteria for a psychiatric disorder.<br>**Prevalence**: 28% (n=26).<br>Delirium most common psychiatric disorder. | Sample size: patients recruited in 13-month period.<br>MMSE tests cognitive function. SCID does not evaluate organic mental disorders. Delirium diagnosis determined by psychiatric assessment.<br>Confidence intervals (CI) not included. |

| Publication | Country | Aim | Design/Screening & Assessment Tools/DSM Criteria | Participants/ Participation Rate | Delirium Prevalence/ Incidence Results | Quality Considerations |
|---|---|---|---|---|---|---|
| Lawlor et al, (2000) | US | Evaluate occurrence, precipitating factors, and reversibility of delirium in an acute PC unit. | Prospective serial assessment in a consecutive cohort. DOCS by trained ward nurses each 8 hour shift, MMSE by medical investigators on admission and twice weekly, MDAS by medical investigators for delirious patients.<br>Semi-structured DSM-IV interview by medical investigators. | Advanced cancer patients (n=104 of 113); 51% male; mean age 62 years, SD ± 1.9 years; participation rate 100% | **Prevalence on admission**: 42% (n=44)<br>**Incidence**: 45% of patients who were delirium free on admission (n=27/60)<br>**Prevalence hours before death**: 88% (n=46/52) | Sample size: patients recruited in 9.5-month period.<br>No psychometric testing of DOCS.<br>MMSE tests cognitive function.<br>MDAS training and moderate-high inter-rater reliability reported separately (Lawlor, Nekolaichuk, et al., 2000). |
| Gagnon et al, (2000) | Canada | Determine delirium frequency and outcome in hospice inpatients | Prospective cohort study. CRS (by trained ward nurses 8th hourly), BOMC to assess orientation, CAM (by two research nurses to diagnose delirium). Training and supervision of research nurses by psychiatric investigator.<br>DSM-III-R | Terminal cancer inpatients (n=89) with a life expectancy <2 months; 48% male; mean (median) age 66 years (68 years); participation rate 95% | **Prevalence**: On admission 20.2% patients (n=18) had delirium symptoms, diagnosis confirmed in 13.3%.<br>**Incidence**: 52.1% of 71 patients delirium free at admission developed delirium symptoms, diagnosis confirmed in 32.8%. | Sample size: patients recruited in 4-month period.<br>CRS requires further validation. |

| Publication | Country | Aim | Design/Screening & Assessment Tools/DSM Criteria | Participants/ Participation Rate | Delirium Prevalence/ Incidence Results | Quality Considerations |
|---|---|---|---|---|---|---|
| Sarhill et al, (2001) | US | 1) Evaluate the use of the BCS; and 2) Determine prevalence, cause, precipitants, and treatment of delirium in an acute PC medicine unit | Prospective assessment by medical officer on admission using the BCS (delirium = score of $\geq$ 2).<br>DSM criteria for delirium not used. | Consecutive patients with advanced cancer (n=41/50); 44% male; median age 65 years; participation rate 82% | **Prevalence**: 31.7% (n=13) on admission | Sample size: patients recruited in 2-month period. Multi-phase sampling not used, delirium screening only. BCS requires further psychometric testing. Not specified who applied BCS (medical clinician, researcher or investigator). No reporting of tool user training or inter-rater reliability testing. CI not included. |
| Durkin, Kearney & O'Siorain, (2003) | UK | Assess prevalence of psychiatric disorder occurring in a PC unit and ascertain whether disorder had been detected and treated prior to admission. | Prospective assessment of patients on admission and twice weekly by principal psychiatric investigator. Presence or absence of a psychiatric diagnosis was determined according to the ICD-10 Diagnostic Criteria for Research.<br>DSM criteria not used. | Inpatients with diagnosis of AIDS or advanced cancer (n=224); 52% male; mean age 66 years, SD $\pm$14.2, range 22-90 years; 100% participation rate. | 62% (n=139) met ICD-10<br>**Prevalence**: 19% (n=43);<br>**Incidence:** 3% patients (n=5/181) developed delirium | Sample size: inpatients recruited in 6-month period.<br>Multi-phase sampling did not occur – delirium-screening tool not used.<br>CI not included. |

| Publication | Country | Aim | Design/Screening & Assessment Tools/DSM Criteria | Participants/ Participation Rate | Delirium Prevalence/ Incidence Results | Quality Considerations |
|---|---|---|---|---|---|---|
| Lam, Tse & Lee, (2003) | Hong Kong | Estimate the incidence and prevalence of delirium in a PC unit and evaluate psychomotor type, aetiologies, reversibility and other characteristics. | Prospective daily assessment of consecutive admissions using structured evaluation, MMSE – Cantonese version, KPS. Patients assessed as delirious had further assessment by medical investigator within the same day to confirm delirium diagnosis. Experienced and trained nurse administered MDAS within 24-hours of delirium diagnosis.<br>DSM-IV | Advanced cancer patients (n=82/102); 46% male; mean age 68 years, SD ± 12.5; participation rate 80%. | **Prevalence**: 58.8% (n=30/51) of patients who died had delirium an average of 12.4 days before death.<br>**Incidence:** 40.2% (n=33)<br>**Subtypes**: 70% hypoactive.<br>**Severity**: 53.3% mild severity, 23.3% moderate, 20% severe | Sample size: inpatients recruited in 4-month period.<br><br>MMSE tests cognitive function.<br><br>Training and supervision of clinical staff conducting daily delirium monitoring was not reported. |

| Publication | Country | Aim | Design/Screening & Assessment Tools/DSM Criteria | Participants/ Participation Rate | Delirium Prevalence/ Incidence Results | Quality Considerations |
|---|---|---|---|---|---|---|
| Spiller & Keen, (2006) | Scotland | Assess the prevalence of hypoactive delirium in specialist PC settings | Study 1: Prospective assessments at admission and 7 days later by study investigator using MMSE, CAM, MDAS, FSS, HADS.<br>Study 2: 48 hour point prevalence study in 8 specialist PC units using MMSE, CAM, MDAS (administered by trained clinical staff, discipline/s not specified).<br>DSM-III-R | Study 1: Hospice inpatients (n=100); 49% male; mean age 68.7 years, SD ± 15 years; 99/100 advanced malignancy; participation rate 88% at admission, 73% at 7 days.<br>Study 2: Inpatients (n=109) of 8 PC units; gender not specified; mean age 68.7 years, diagnoses not specified; participation rate 87%. | Study 1: **Prevalence**: 29% (n=29) at admission - 86% hypoactive, 14% mixed.<br>26% (n=19/73) had delirium 7 days later - 68% hypoactive, 21% hyperactive, 11% mixed.<br>**Incidence**: 7% (n=5 /73) within 7-days of admission<br>Study 2: **Point prevalence**: 29.4% (n=32) (range 14-35%). 78% hypoactive. 6% hyperactive, 16% mixed. | Determination of sample size of 100 for Study 1 was not explained.<br>MMSE tests cognitive function.<br>No reporting of researcher training in use of CAM, MDAS in Study 1.<br>Diagnoses of study population not reported in Part 2.<br>CI included in Part 1, but not Part 2. |

| Publication | Country | Aim | Design/Screening & Assessment Tools/DSM Criteria | Participants/ Participation Rate | Delirium Prevalence/ Incidence Results | Quality Considerations |
|---|---|---|---|---|---|---|
| Fang et al, (2008) | Taiwan | Determine the prevalence, detection and treatment of delirium in an acute PC/hospice unit | Survey and chart review, screening by trained research nurse using the DRS-CV at admission and second daily, followed by psychiatrist review for +ve DRS-CV to verify diagnosis and determine delirium sub-type.<br>DSM-IV | Terminal cancer inpatients (n=228/457); 51% male; mean age 64.57 SD ±14.88; participation rate 49.9% | **Prevalence**: 46.9%.<br>**Subtypes**: 68.2% hypoactive, 21.5% hyperactive, 10.3% mixed. | Sample size: inpatients recruited in 6-month period.<br>Largest sample within included studies, but participation rate <80%. 51% of non-participants too ill to consent indicating selection bias. |

**BOMC** Blessed Orientation Memory Concentration **BCS** Bedside Confusional Scale **CAM** Confusion Assessment Method **CRS** Confusion Rating Scale **DOCS** Delirium Observational Checklist Scale **DRS-CV** Delirium Rating Scale-Chinese Version **DS** Delirium Scale **DSM** Diagnostic and Statistical Manual **FSS** Fatigue Severity Scale **HADS** Hospital Anxiety and Depression Scale **KPS** Karnofsky Performance Scale **MDAS** Memorial Delirium Assessment Scale **MMSE** Mini-Mental State Examination **PC** Palliative Care **SCID** Structured Clinical Interview for DSM-III-R **UK** United Kingdom **US** United States

### 2.6.4 Screening and assessment tools

Eight different tools were used across the studies to assess cognition, screen for or confirm delirium (Table 2.1). Of the six delirium specific screening or assessment tools, all varied in their validity, purpose (screening, diagnosis, severity), intended rater (psychiatrically vs. non-psychiatrically trained), ratings procedures (observation vs. interview), number of items and extent to which they correlate with different versions of DSM criteria for delirium (Adamis, Sharma, Whelan, & MacDonald, 2010).

Three delirium or 'confusion' screening tools included the Confusion Rating Scale (CRS) used by ward nurses (Gagnon, et al., 2000; Williams, 1991); the Bedside Confusion Scale (BCS) used by medical investigators (Sarhill, et al., 2001; Stillman & Rybicki, 2000); and the Delirium Observational Checklist Scale, an instrument developed by study investigators for ward nurse use (Lawlor, Gagnon, et al., 2000) Although the BCS was previously validated in the palliative care setting it requires further investigation of its psychometric properties (Adamis, et al., 2010). The CRS requires further validation and the DOCS is not a validated delirium-screening tool (Adamis, et al., 2010).

Two cognition assessment tools, used to either screen for delirium or to assist delirium assessment, were the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & Mc Hugh, 1975) used by psychiatric and medical investigators (Lam, et al., 2003; Lawlor, Gagnon, et al., 2000; Minagawa, et al., 1996; Spiller & Keen, 2006) or clinical staff (Spiller & Keen, 2006) and the Blessed Orientation Memory Concentration (BOMC) test which was used by research nurses (Gagnon, et al., 2000; Katzman, Brown, & Fuld, 1983).

Three delirium assessment tools were the Confusion Assessment Method (CAM) (Inouye et al., 1990) used by research nurses (Gagnon, et al., 2000) or medical investigators and trained clinical staff (Spiller & Keen, 2006); the Memorial Delirium Assessment Scale (MDAS) (Breitbart et al., 1997; Lawlor, Nekolaichuk, et al., 2000) used by medical investigators (Lawlor, Gagnon, et al., 2000; Spiller & Keen, 2006), trained clinical staff (Spiller & Keen, 2006) or a research nurse (Lam, et al., 2003); and the Delirium Rating Scale (DRS) (Trzepacz, Baker, & Greenhouse,

1988) (Chinese Version) used by a research nurse (Fang, et al., 2008). Only the MDAS (Breitbart, et al., 1997; Lawlor, Nekolaichuk, et al., 2000) and the DRS (Grassi et al., 2001; Trzepacz et al., 2001) were validated in palliative care or advanced cancer populations prior to use in the studies under examination, with the MDAS later undergoing further validation (Lawlor, Nekolaichuk, et al., 2000). The CAM is validated in many clinical settings and languages and was subsequently validated in a palliative care setting (Adamis, et al., 2010; Ryan et al., 2009).

No studies reported perspectives of patients or families of the acceptability of delirium screening and assessment processes.

### 2.6.5 Delirium prevalence and incidence rates

The prevalence and incidence rates reported in the included studies are represented graphically in Figure 2.2.

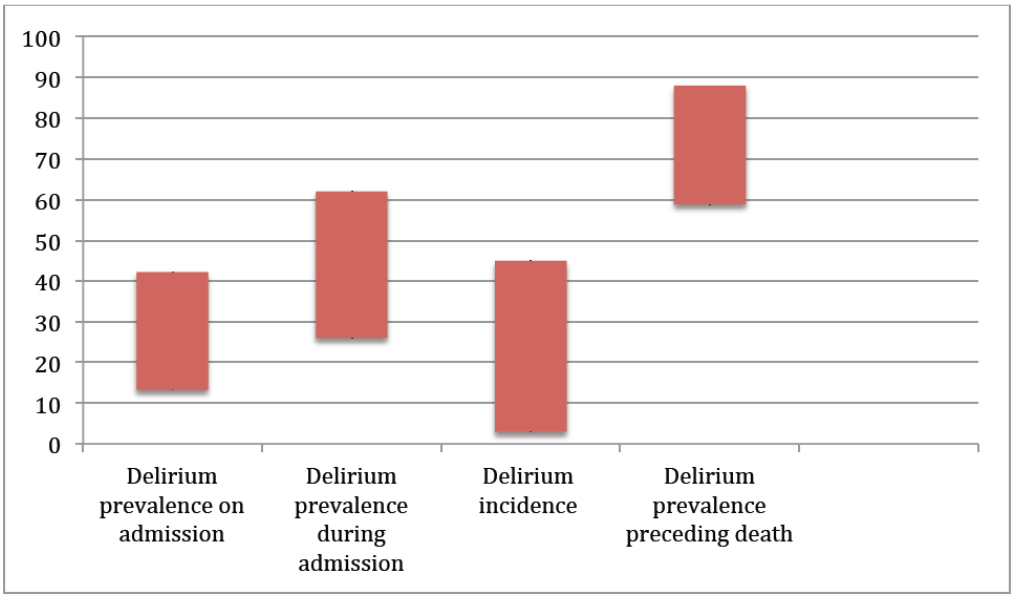


***Figure 2.2 Graphical representation of the range of delirium prevalence and incidence in palliative care inpatient units***

*On Admission*

Five studies measured delirium prevalence at admission, ranging from 13.3-42.3% of patients (Durkin, et al., 2003; Gagnon, et al., 2000; Lawlor, Gagnon, et al., 2000; Sarhill, et al., 2001; Spiller & Keen, 2006). Of 104 advanced cancer admissions to an acute palliative care unit delirium was present at admission in 42.3% of patients (Lawlor, Gagnon, et al., 2000). A later study consecutively measured delirium frequency in hospice inpatients (n=89) and 13.3% were confirmed to have delirium (Gagnon, et al., 2000). In another, 19% of patients (n=224) admitted to a palliative care unit had delirium (Durkin, et al., 2003). One third (32%) of participants (n=41) were classified as delirious according to presence of inattention and altered level of alertness in one acute palliative care unit (Sarhill, et al., 2001), while 29% of participating patients (n=100) admitted to a Scottish hospice had delirium (Spiller & Keen, 2006).

*During admission*

Delirium prevalence across the whole cohort of palliative care inpatients during each study period ranged from 26-62% (Fang, et al., 2008; Gagnon, et al., 2000; Minagawa, et al., 1996; Spiller & Keen, 2006). One study measuring psychiatric morbidity at one point during the week after admission to a palliative care unit found that delirium was the most prevalent psychiatric disorder, occurring in 28% of all participants and representing 52% of all psychiatric diagnoses (Minagawa, et al., 1996). Another, screening each 8-hour shift, identified that 62% of participants developed delirium at some point during hospice admission (Gagnon, et al., 2000). One study reassessed hospice patients (n=73) seven days after admission and found that 26% had delirium, while across 8 hospices or inpatient palliative care services 29.4% of patients had a delirium diagnosis during a 48 hour period of assessment (Spiller & Keen, 2006). Most recently, 46.9% of palliative care inpatients (n=228) screened second daily were found to have delirium (Fang, et al., 2008).

Three studies examined occurrence of different subtypes. All reported the majority of delirious patients experienced the hypoactive subtype (68-86%) (Fang, et al., 2008; Lam, et al., 2003; Spiller & Keen, 2006).

Five studies measured delirium incidence after admission and reported rates of between 3-45% (Durkin, et al., 2003; Gagnon, et al., 2000; Lam, et al., 2003; Lawlor, Gagnon, et al., 2000; Spiller & Keen, 2006). Delirium developed during admission

in 45% of patients (n=60) (Lawlor, Gagnon, et al., 2000). In a later study involving 71 participants, 32.8% developed delirium (Gagnon, et al., 2000). Both studies included screening by ward nurses each 8-hour shift. A study using daily screening reported that 40.2% (n=82) of admitted patients developed delirium (n=33/82). The majority (70%) had the hypoactive subtype, of mild severity (53.3%) (Lam, et al., 2003). In contrast, one study reported development of five new cases in 73 patients within a 7-day period, which is an incidence of 7% (Spiller & Keen, 2006). Using twice weekly assessment and the ICD-10 diagnostic criteria, another reported incidence of only 3%: during the six month study period only five of 181 patients delirium free on admission subsequently developed delirium (Durkin, et al., 2003).

*Preceding death*

Two studies measured prevalence of delirium in the weeks or hours before death and reported rates of 58.8-88% (Lam, et al., 2003; Lawlor, Gagnon, et al., 2000). The most recent study reported 58% prevalence in patients (n= 51) who died during admission (Lam, et al., 2003). Only one study has explicitly measured and reported occurrence in the last 6 hours of life in an acute palliative care unit and reported that the majority of patients had delirium (88%) (Lawlor, Gagnon, et al., 2000).

### 2.6.6 Variation in delirium prevalence and incidence

Studies that used DSM-IV criteria reported higher prevalence (42-88%) (Fang, et al., 2008; Lam, et al., 2003; Lawlor, Gagnon, et al., 2000) and incidence (40.2-45%) (Lam, et al., 2003; Lawlor, Gagnon, et al., 2000); compared to studies using earlier versions of DSM criteria and ICD-10 (prevalence 13.3-29.4% (Durkin, et al., 2003; Gagnon, et al., 2000; Minagawa, et al., 1996; Spiller & Keen, 2006) and incidence 3% -32.8%) (Durkin, et al., 2003; Gagnon, et al., 2000; Spiller & Keen, 2006). Studies screening participants daily or more often reported higher incidence (32.8-45%) (Gagnon, et al., 2000; Lam, et al., 2003; Lawlor, Gagnon, et al., 2000) than studies that screened or assessed delirium participants less frequently (3-7%) (Durkin, et al., 2003; Spiller & Keen, 2006). Delirium prevalence on admission varied slightly across settings: palliative care unit (19%), hospice (13.3-29%) and acute palliative care units (31.7-42%).

### 2.6.7 Role of clinicians in the identification and diagnosis of delirium

In four studies clinicians were actively involved in screening and assessment study processes (Gagnon, et al., 2000; Lam, et al., 2003; Lawlor, Gagnon, et al., 2000; Spiller & Keen, 2006). In two studies ward nurses screened using the DOCS (Lawlor, Gagnon, et al., 2000) or the CRS after received training in use of tools and features of delirium (Gagnon, et al., 2000). An experienced and trained nurse assessed delirious patients using the MDAS to measure delirium severity in another (Lam, et al., 2003). In the study involving 8 separate Scottish hospices and palliative care services clinicians received training prior to using the CAM and MDAS to identify and assess delirium over a 48-hour period (Spiller & Keen, 2006).

Research nurses were also involved in delirium screening and assessment (Fang, et al., 2008; Gagnon, et al., 2000; Lam, et al., 2003). Delirium diagnosis was established by nurses in one study using the CAM in consultation with the psychiatric investigator if there was uncertainty about the diagnosis (Gagnon, et al., 2000). Nurses measured delirium severity in another using the MDAS 24-hours after delirium diagnosis by a physician (Lam, et al., 2003); and the DRS was used to screen inpatients for delirium (Fang, et al., 2008).

## 2.7 Discussion

There were some similarities across studies, with most adopting a two-phase sampling method: screening followed by confirmation, and involved patients of a similar age and primary cancer diagnosis. There was varying methodological quality across these studies, with heterogeneity of diagnostic criteria, sample sizes, frequency of assessment and measurement tools adopted. Despite these differences and the variation in reported occurrence, categorising delirium prevalence at different points along the palliative care inpatient trajectory indicates that prevalence is lower at admission (range 13 - 42%) (Durkin, et al., 2003; Gagnon, et al., 2000; Lawlor, Gagnon, et al., 2000; Sarhill, et al., 2001; Spiller & Keen, 2006), increases during admission (range 26-62%) (Fang, et al., 2008; Gagnon, et al., 2000; Minagawa, et al., 1996; Spiller & Keen, 2006), with greater prevalence in those patients who died (range 59-88%) (Lam, et al., 2003; Lawlor, Gagnon, et al., 2000). This review has confirmed that palliative care inpatient populations have delirium incidence and prevalence equal to or greater than other known high-risk populations, such as older people admitted to hospital (Clinical Epidemiology and Health Service Evaluation

Unit Melbourne Health, 2006), Intensive Care Units (Ely et al., 2001; McNicoll, 2005), post hip surgery (Galanakis, Bickel, Gradinger, Von Gumppenberg, & Förstl, 2001; Santana, 2005) and long-term care (McCusker et al., 2011).

The review confirms hypoactive delirium as the most prevalent subtype in palliative care populations (Fang, et al., 2008; Lam, et al., 2003; Leonard, Donnelly, Conroy, Trzepacz, & Meagher, 2011; Spiller & Keen, 2006). While hypoactive delirium may appear less severe than other subtypes (Lam, et al., 2003) and cause less difficulties in ward management (Meagher et al., 2011), it is associated with increased mortality (Fang, et al., 2008). Patients value being cognitively able at the end of life; therefore hypoactive delirium adversely impacts upon them since cognitive changes occur as often as in the hyperactive and mixed subtypes (Leonard, et al., 2011; Steinhauser et al., 2000).

Clinician involvement in delirium screening and assessment in half of these studies highlights potential for routine screening by clinicians outside the research context. Delirium recognition by non-psychiatric clinicians is clearly possible and appropriate with training and access to validated tools (Breitbart, et al., 1997; Lawlor, Nekolaichuk, et al., 2000; Ryan, et al., 2009). Other studies have reported delirium screening by nurses in a hospice setting to be feasible (Gagnon, Allard, Gagnon, Merette, & Tardif, 2012; Rao, Ferris, & Irwin, 2011).

The challenges of screening for delirium in palliative care populations are evidenced by the small proportion of studies that reported delirium occurrence in patients who were dying. The proportion of patients and/or families who declined to participate in the assessment processes suggests delirium assessment for research purposes is not always acceptable to them. Many patients were too unwell to provide consent or were excluded because they were dying, comatose or could not speak, reflecting the reality of the fragility of many palliative care patients. Similarly, a recent study reported a low rate of CAM completion by hospice nurses (39%). These challenges highlight the difficulty of conducting this assessment in the last days of life and the need for validated low-burden delirium assessment tools at this time (Gagnon, et al., 2012).

Applying the DSM-IV criteria appears to lead to increased case finding compared to other delirium diagnostic criteria, which has been previously reported (Cole, Dendukuri, McCusker, & Han, 2003). Interestingly, the variability in prevalence and

incidence noted in this review reflect results of similar reviews that included studies using less specific delirium definitions (Hjermstad, et al., 2004; Leonard, et al., 2008).

### 2.7.1 Implications for clinical practice and research

As screening is the first step in the delirium ascertainment process and daily screening increases detection of incident delirium, the question is raised: should routine delirium screening should be implemented in palliative care inpatient settings? Clinical practice guidelines for other high-risk patient populations recommend screening to improve early recognition of delirium, (Canadian Coalition for Seniors' Mental Health, 2010; Clinical Epidemiology and Health Service Evaluation Unit Melbourne Health, 2006; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010) although the extent to which this has been routinely adopted is unknown. Before proceeding to implement routine screening and other assessment processes routinely in clinical practice a number of other key questions require investigation, including: which methods of screening and assessment are most acceptable to patients and family and cause minimal harm; if it is cost effective; if early recognition and treatment of delirium improves patient outcomes; and what are the most effective and safe delirium treatment for palliative care inpatients (Harris, 2001; Wilson & Jungner, 1968).

Further investigation of delirium prevention and non-pharmacological interventions in palliative care is needed (Gagnon, et al., 2012). Measuring the impact of interventions on delirium incidence, severity and patient mortality should continue to be a focus of research, yet as improvements in morbidity and mortality are likely to be minimal in this population and the focus of care is relief of distress and suffering, patient and family subjective experiences (such as perceptions of care, distress, dignity and quality of life) related to delirium screening, recognition and treatment are especially important outcomes to determine (World Health Organisation, 2002). Research into pharmacological interventions must also continue, in view of commonly prescribed antipsychotics being recently reported as increasing the severity of delirium symptoms (Agar et al., 2015), and benzodiazepines and methylphenidate being used in clinical practice despite lacking high-level evidence of their efficacy and safety for delirious palliative care patients (Elie, Gagnon, Gagnon, & Giguuere, 2010; Lonergan, Luxenberg, & Areosa Sastre, 2009).

Development of observational delirium screening and assessment strategies that are sensitive to the needs of palliative care patients who are very ill, dying or unable to communicate is also required (Harris, 2001; O' Malley, Leonard, Meagher, & O' Keeffe, 2008; Wilson & Jungner, 1968). This review has highlighted the lack of consensus regarding selection of delirium screening, assessment, diagnostic and confirmation tools in palliative care research. The uncertainty is likely to be reflected in clinical practice. Establishing the acceptability of various delirium tools for patients and families would inform the sector about which are the most appropriate to use in this population, particularly in the dying stage. Bringing about consensus would then facilitate delirium benchmarking, quality improvement and consistency of research methodology (Cicely Saunders Institute; Eagar, 2010).

To further improve methodological and reporting quality of future delirium epidemiological research in palliative care populations, consideration of recently developed guidelines for observational studies in epidemiology is recommended (Vandenbroucke et al., 2007; von Elm, et al., 2007).

### 2.7.2 Study limitations and strengths

Limitations of this review include exclusion of papers not published in English, potentially contributing to selection bias, and the absence of multiple independent raters in the extraction of data to assess eligibility and quality of included studies. There are limitations related to generalizability of this review due to the focus on advanced cancer diagnoses within study populations. As the brief of palliative care shifts to non-malignant conditions and settings where end of life care is routinely provided, such as geriatric, intensive and long term care settings, it is important to consider the implications of this changing population (Janssen, Spruit, Wouters, & Schols, 2008; Murray, 2005; World Health Organisation, 2011). Although results suggest delirium prevalence is greater for patients closer to death, this was not confirmed within this review due to variable reporting of participants' functional status and illness staging, and variation in operational definitions of 'terminal'. This barrier has been previously noted with a recommendation that all future delirium occurrence studies incorporate a patient cohort classification system based on estimated prognosis (Hjermstad, et al., 2004).

Despite these limitations this review has the strengths of the use of a systematic approach with application of accepted guidelines and a structured approach to the assessment of quality of included studies (Stroup, et al., 2000; von Elm, et al., 2007).

## 2.8 Conclusion

Chapter two has reported a systematic review examining the methods, quality and results of studies prospectively measuring delirium occurrence in palliative care inpatient units or hospices. The moderate to high rate of delirium occurrence supports the need for delirium evidence to inform recognition and assessment systems and practice in inpatient palliative care. To advocate for this system and practice change at the local level, confirmation of the delirium occurrence rate in the Australian palliative care inpatient population is also needed.

The DePAC project was initiated and designed with the aim of identifying the actions required to build palliative care nurses' capabilities in delirium recognition and assessment. A knowledge translation process was therefore considered the best approach to determine the specific nature of the delirium evidence-practice gaps and best ways to address those identified (Grimshaw, Eccles, Lavis, Hill, & Squires, 2012). The following chapter outlines the design, knowledge translation conceptual framework and methods of the DePAC project, which were chosen to answer the research questions and sustain the ultimate focus of moving delirium evidence into inpatient palliative care nurses' practice.

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# Chapter 3: Design, conceptual framework and methods

## 3.1 Introduction

The systematic review reported in Chapter two revealed that delirium is experienced by many palliative care inpatients and increases as patients near death (Hosie, Davidson, Agar, Sanderson, & Phillips, 2013). However, the fluctuating nature of delirium and lack of consensus about best screening and assessment practices contributes to the challenges and varying ways to confirm its presence in palliative care inpatients. This ambiguity in part explains why the steps required for palliative care nurses' optimal recognition and assessment of delirium have not been clearly defined and translated into action.

The DePAC project focused upon identifying the actions required to build palliative care nurses' capabilities in delirium recognition and assessment. Adopting a systematic approach such as *knowledge translation,* which links research and practice change, was considered the approach to identify and determine the best way to address evidence-practice gaps at the system and clinical practice levels (Grimshaw, Eccles, Lavis, Hill, & Squires, 2012).

This chapter outlines the design, conceptual framework and methods of the DePAC project.

## 3.2 Aim

The DePAC project aimed to identify the actions required to improve the capabilities of specialist inpatient palliative care nurses to recognise and assess delirium.

## 3.3 Design

The four year, two phase DePAC project employed a sequential transformative mixed methods design underpinned by a knowledge translation framework (Canadian Institutes for Health Research, 2014; Straus, Tetroe, & Graham, 2009). An overview of the interrelationship between the DePAC research questions, phases, methods and knowledge translation activities are illustrated in Table 3.1.

***Table 3.1 The DePAC project research questions, phases, methods and knowledge translation activities***

| **Research question** | **Phase** | **Method** | **Knowledge translation activities** |
|---|---|---|---|
| 1. What is the epidemiology of delirium in the palliative care inpatient population? | Phase 1 | Study 1: Systematic review (QUANT)<br>Study 2: Environmental scan (QUAL)<br>Study 3: Cross sectional study (QUANT) | • Identify problem<br>• Identify, review, select knowledge<br>• Knowledge inquiry and synthesis<br>• Knowledge tools |
| 2. Is delirium recognition and assessment guidance available to nurses working in palliative care inpatient settings? | | | |
| 3. What are the experiences, views and capabilities of nurses in recognising and assessing palliative care inpatients' delirium? | Phase 2 | Study 4: Critical incident technique using a delirium vignette (QUAL)<br>Study 5: Focus groups (QUAL) | • Knowledge inquiry<br>• Assess barriers and enablers to knowledge use |
| 4. What are the barriers and enablers to nurses recognising and assessing delirium in the palliative care inpatient setting? | | | |
| 5. What is required to improve the capabilities of nurses to recognise and assess delirium in palliative care inpatient settings? | Conclusion | Data integration and meta-inference | • Knowledge synthesis<br>• Continue knowledge to action process |

## 3.4 Settings and participants

The DePAC project focused upon the specialist palliative care inpatient unit setting with respect to: i) epidemiology of delirium; ii) systems supporting the recognition and assessment of delirium; and iii) nurses' delirium recognition and assessment practices. Various participants and sites were involved during the DePAC project's two phases.

Phase 1 participants included:

Health professionals (physicians, nurses, social worker, and physiotherapist) from three palliative care inpatient units in Sydney, Australia (Study two); and

Adult inpatients of two palliative care units in Sydney, Australia (Study three);

Phase 2 participants included:

Nurses from nine Australian palliative care inpatient services (Study four); and

Nurses from two palliative care units in Sydney, Australia (Study five).

Three specialist palliative care inpatient units were the principal sites involved in the DePAC project. The participating units were situated in Sydney, NSW, Australia and shared the following characteristics:

*Level 3 palliative care services*, meaning they are highly resourced (e.g. medical and nursing specialists with qualifications in palliative care; expanded specialist allied health staff; and have a lead role in palliative care education and research) with a corresponding high expectation of capability (NSW Department of Health, 2007; Palliative Care Australia, 2005);

*Affiliated health organisations*, being run by not-for-profit religious organisations as part of the public NSW health system (NSW Health, 2012);

Undertaking the *Palliative Care Outcomes Collaborative* (PCOC), which enables daily screening of patients' symptoms for clinical intervention, benchmarking and quality improvement purposes (Palliative Care Outcomes Collaborative, 2014); and

*Active clinical trials unit*: At the time of data collection, the sites were all actively recruiting patients into a randomised controlled trial of antipsychotics for targeted delirium symptoms (Agar et al., 2015).

*Selecting the participating sites and samples*

The need to manage the complex clinical site governance requirements in Studies two, three and five largely limited study recruitment to these three sites. These inpatient units were selected as the participating sites primarily because they are highly resourced with a high level of palliative care capability and the researcher's doctoral supervisors' roles at these sites supported the researcher's access. Initial contact was made with managers of these potential sites and each site was free to determine their capacity to contribute to the research.

In Study four this direct recruitment approach was augmented with recruitment of participant nurses via a nursing social media site (Hosie, 2013). The second recruitment strategy was designed to increased sample heterogeneity by ensuring nurses working across different geographical areas and palliative care units situated in non-metropolitan regions could participate (Kemppainen, 2000).

## 3.5 Using a mixed methods design within The DePAC project

This section describes mixed methods research and its application within the DePAC project.

### 3.5.1 Defining mixed methods research

Mixed methods research uses and integrates quantitative and qualitative methods, either within a single study or a multi-study research project, so that the understanding gained is greater than simply the sum of its parts (Creswell, 2009). A simple conceptualisation of the relationship between the three broad research paradigms (quantitative, qualitative and mixed methods) is of mixed methods research being located midway along the qualitative-quantitative continuum (Figure 3.1) (Johnson, Onwuegbuzie, & Turner, 2007). A mixed methods stance selects and employs the approach or approaches best suited to answer the research question/s and meet the needs of the population for whom the research is conducted (Creswell, 2009; Johnson & Onwuegbuzie, 2004).

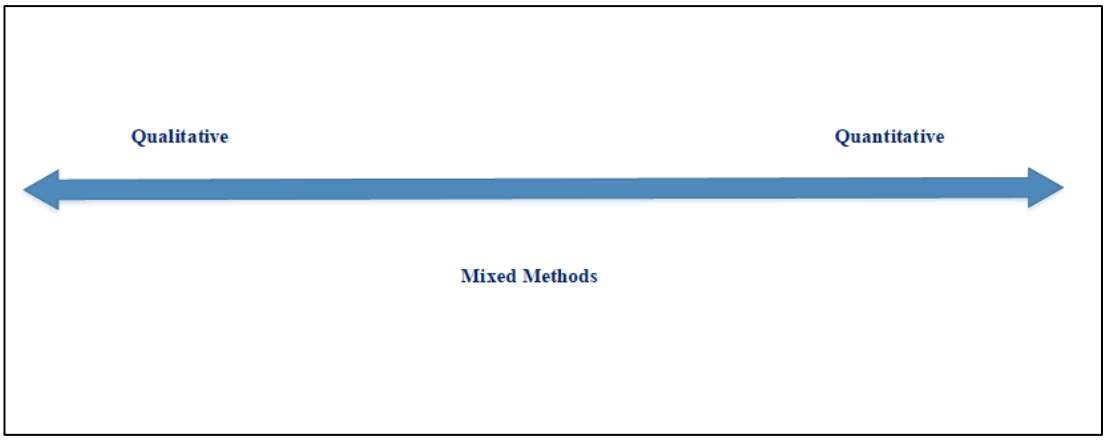


***Figure 3.1 Simplified conceptualisation of the continuum of quantitative, qualitative and mixed methods research***

Source: Johnson et al (2007)

### 3.5.2 Evolution of mixed methods

Mixed methods research has developed over the last 50 years to become the 'third research paradigm' (Johnson & Onwuegbuzie, 2004). Many mixed methods researchers recall the philosophical and methodological battlefields of the 1970's and 80's, where proponents of positivist paradigms versed social scientists advocating for experiential understanding for supremacy in the 'hierarchy' of knowledge (Hall, 2012; Muncey, 2009). During the intervening decades these robust debates have evolved into acceptance that these objective and subjective standpoints can be together employed as complementary paradigms. It is now accepted that combining quantitative (i.e. deductive, numerical, objective, measuring relationships between variables) and qualitative research (i.e. inductive, words, exploring individual experience and meaning) is required to answer some research questions. The integration of differing data types and sources ideally leads to a greater depth, richness and completeness of understanding of the peoples and topics researched (Creswell & Plano-Clarke, 2006).

While quantitative research methods to some extent continues to be privileged in the hierarchy of health care evidence (National Health and Medical Research Council, 2000), the value of mixed methods research is exemplified in the United Kingdom's Medical Research Council's Framework for Complex Interventions, which addresses the challenges of measuring feasibility, effectiveness, safety and implementation of multi-component interventions across more than one setting (Craig et al., 2008). Strategic partnering of quantitative and qualitative methods makes complex research

endeavours more possible and thereafter more generalisable for patients, systems and practice. In this way, the primary goal of health care research to understand and meet the complex and holistic needs of people may be better achieved.

### 3.5.3 The paradigmatic basis for mixed methods research

Paradigms incorporate researchers' shared beliefs and perspectives of the world, reality, the nature of knowledge, methodology and solutions to problems (Creswell, 2011). No one scientific paradigm explains the complete enormity and complexity of reality, making it impossible for any researcher to argue that their chosen approach encompasses absolute truth and rightness (Muncey, 2009). This human limitation explains why scientific paradigms are debated and evolve and why the paradigmatic basis for mixed methods research itself is evolving, contentious and indeterminate (Hall, 2012; Muncey, 2009).

The three paradigms that have most influenced mixed methods within the social sciences are the pragmatism, transformative and realism worldviews (Greene & Caracelli, 2003; Hall, 2012):

*Pragmatism* discounts notions of 'truth' or 'reality' to instead prioritise 'what works' practically in the answering of a research question (Creswell, 2009). Pragmatism allows for multiple viewpoints and acknowledges that the values of the researcher are influential in the interpretation of results (Tashakkori, 2003). Valid critiques of pragmatism are the relativism of its discounting of truth and rationality, and that what works in the answering of a research question cannot always be determined in advance (Hall, 2012; Muncey, 2009).

The *transformative-emancipatory* paradigm uses mixed methods to focus upon the lives and experiences of under-represented and/or marginalised populations, such as the disabled and the poor, to promote change at both the individual and the systems level (Mertens, 2010). As such, this paradigm limits the application of mixed methods research to these particular populations.

Whereas a *realism* paradigm has a dual focus upon sense-making and values and recently has been proposed as the most appropriate single paradigm for mixed methods research (Greene & Caracelli, 2003; Hall, 2012; Mark, Henry, & Julnes, 1999). Alternatively, there may be no stated paradigm; or, there may be use of more than one within mixed methods studies (Creswell, 2011; Hall, 2012).

In practice, paradigms are not usually what compels health care researchers to employ mixed methods (Greene & Caracelli, 2003). Decisions about research methods are most often based upon more prosaic factors, such as the: research aim and question, needs and characteristics of the study population, feasibility, ethical considerations and resources, including the methodological expertise within the research team.

### 3.5.4 Rationale for using mixed methods in the DePAC project

The decision to use a mixed methods design in the DePAC project was likewise not based primarily upon paradigmatic considerations. Mixed methods was chosen to answer five distinct research questions, related to i) epidemiological; ii) systems; and iii) nursing practice aspects of delirium recognition and assessment within the palliative care unit (Bryman, 2006). The DePAC project therefore most closely aligns to a pragmatic worldview (Creswell, 2009).

Some questions were best answered by quantitative methods, such as investigating the prevalence and incidence of delirium (Studies one and three). While questions about nurses' experiences and barriers and enablers to delirium practice were best answered by an interpretive approach (Studies two, four and five). This approach was undertaken for *complementarity*, as neither qualitative nor quantitative data alone were sufficient to address the research problem (Halcomb & Andrew, 2009a). An alternative framing of the rationale for the use of mixed methods was that of *completeness*, so that a more comprehensive interpretation of the DePAC data could be generated (Bryman, 2006). Each of the five studies within the DePAC project stands alone, with the overall aim of this doctoral research project being addressed through data integration and meta-inference. Adopting a mixed methods design was considered essential to providing a more coherent understanding of the phenomenon of delirium and nursing practice and systems in Australian palliative care inpatient units (Bryman, 2006).

### 3.5.5 Mixed methods procedures within the DePAC project

The choice of a sequential transformative design for the DePAC project denotes that the discrete phases were staged sequentially with the intent of investigating delirium epidemiology and systems during Phase one and exploring nursing practice during Phase two (Table 1.1 and Figure 3.2 below). While the phases of the DePAC project

were sequential, mixed methods data collection also occurred concurrently within Phase one (between Studies one, two and three). The sequential transformative mixed methods design compelled the use of a theoretical or conceptual framework (Creswell, 2009). Knowledge translation was selected as the DePAC project conceptual framework because it both fitted the phenomena of interest and was congruent with a sequential transformative mixed methods design. The DePaC project qualitative and quantitative data were considered to be of equal significance and importance at all times.

The reporting of the DePAC project within this thesis was guided by recommendations that mixed methods research designs be clearly described and justified, the paradigmatic basis made explicit, and quantitatively and qualitatively derived data be integrated (O'Cathain, Murphy, & Nicholl, 2008). Data were summarised and integrated upon completion of all five studies to gain an overview of the DePAC Project as a whole (Cameron, 2009). A diagrammatic representation of the mixed methods approach to sequence, priority, and stage of integration and use of a theoretical perspective within the DePAC project is contained within Figure 3.2, below.

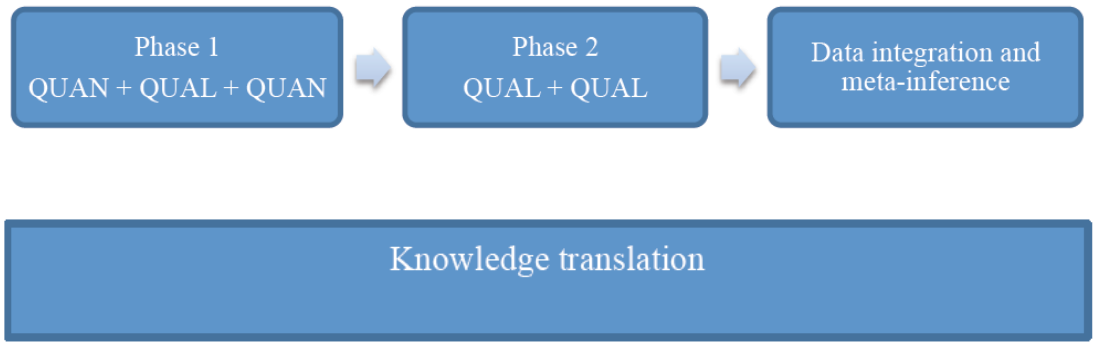


***Figure 3.2 Sequential transformative mixed methods design of the DePAC project***

### 3.5.6 Advantages and challenges of using a mixed methods design

Adopting a mixed methods approach within the DePAC project was considered advantageous in view of delirium being a complex clinical syndrome and delirium care being multi-faceted in the palliative care setting. The mixed methods approach allowed for greater insights and breadth of understanding of the research problem (Creswell & Plano-Clarke, 2006; Johnson & Onwuegbuzie, 2004). A mixed methods design offered the potential to allow for broader research questions comprising epidemiological, systems and nursing practice aspects of delirium in inpatient palliative care to be answered.

A major challenge of a doctoral mixed methods research project is that it requires the researcher to learn about quantitative, qualitative approaches and mixed methods within the bounded time frame of a higher research degree (Johnson & Onwuegbuzie, 2004). Developing an understanding of the history, theories and language associated with each method, and mastering their technical and reporting processes can be particularly challenging for novice researchers (Creswell, 2009; Halcomb & Andrew, 2009b). A mixed methods project is often more complex and lengthy because the integration of data requires an additional level of analysis.

Solutions to address these challenges included the researcher committing to extensive reading, attendance at academic workshops (e.g. statistical analysis, mixed methods research, qualitative research) and generating manuscripts for peer-reviewed journals. The establishment of an interdisciplinary (nursing, medical and allied health) supervisory team experienced in different methodological approaches, including mixed methods, and with the capacity to provide informed guidance to the researcher throughout the DePAC project, was considered essential (Halcomb & Andrew, 2009b).

## 3.6 The DePAC project: guided by knowledge translation

Using a sequential transformative mixed methods design meant the philosophical and methodological premises of knowledge translation were the guiding force for the DePAC project, rather than the use of mixed methods per se (Creswell & Plano-Clarke, 2006). The following section describes knowledge translation, the DePAC project data collection methods, and how the studies were situated within the knowledge translation conceptual framework.

### 3.6.1 The development of knowledge translation and evidence-based practice

The last 70 years has seen exponential growth in health care research, evidence-based practice and the science of embedding knowledge into health care actions (Cochrane Library, 2015; Estabrooks et al., 2008; Stolberg, Norman, & Trop, 2004). *Knowledge translation* is a broad term for a range of activities that aim to move research evidence ('knowledge') into routine use ('action'), for the betterment of society and the people whom the action serves (Estabrooks, et al., 2008). *Evidence-based medicine* (alternatively, *evidence-based practice*) seeks to unite the best available evidence, wisdom acquired through clinical experience, and consideration of patients' individual needs, circumstances and preferences (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). The primary driver for knowledge translation and the evidence-based practice movement is that expansion in scientific knowledge does not in and of itself lead to improvements in health care actions and patients' health, well-being and/or comfort (Canadian Institutes for Health Research, 2014; Runciman, 2012).

There are several reasons why the goals of health care – which are to promote optimal health and development throughout the human lifespan, and cure, heal, comfort and alleviate the suffering of people who are sick or dying - are not always achieved. In the first instance, health care cannot cure all ills, nor relieve all pain and suffering experienced by human beings. Secondly, missing systems and practice can cause harm (Graham et al., 2006). Some health care has iatrogenic effects, which may manifest as harm to the patient, including death (Global Burden of Disease 2013 Mortality and Causes of Death Collaborators, 2014). Health care goals may also not be achieved because prevailing attitudes, habits and cultures of health care settings and professionals prevent new evidence from being generated and adopted, and old ineffective practices from being relinquished.

Collectively, these factors explain why the average time from discovery of evidence to implementation in practice is estimated to be 17 years (Morris, Wooding, & Grant, 2011). Time lags contribute to poorer outcomes for patients, inequity and inefficiencies within health care, and waste the cost and efforts of research (Ward, House, & Hamer, 2009). An increasing volume of health care evidence, complexity and choices, finite resources, and recognition of evidence-practice gaps heighten the need for effective strategies to integrate knowledge into health care actions (Graham,

et al., 2006; Tieman, Sladek, & Currow, 2009). The need to embed new evidence into practice in a timely manner has thereby seen the emergence of knowledge translation as an important conceptual framework.

### 3.6.2 Defining knowledge translation within the DePAC project

The DePAC project adopted the Canadian Institutes for Health Research (CIHR) definition of knowledge translation, as this definition is most widely used and closely aligned to the inpatient context of care (Research Into Action - A Knowledge Translation Initiative, 2005). The definition is:

A dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products, and strengthen the health care system (Canadian Institutes for Health Research, 2014).

While knowledge can be conceptualised in many different ways (Greenhalgh & Wieringa, 2011), the DePAC project defines knowledge as that derived from scientific and ethically sound research (Graham, et al., 2006). 'Ethically sound' means knowledge must correspond with ethical principles, universal human values, social norms, and legal and regulatory frameworks before, during and after being implemented into action (Trevor-Deutsch, Allen, & Ravitsky, 2011).

The action in knowledge translation encompasses that taken by health care organisations and clinicians, policymakers, patients, carers and the wider community ('stakeholders') (Graham, et al., 2006). Action must be compelled by and explicitly grounded in the best interest of the patient (or recipient) and according to the best available evidence (Banja & Eisen, 2013). The DePAC project primarily refers to action undertaken through policy, and by health care organisations and clinicians.

### 3.6.3 The knowledge to action process

Knowledge translation incorporates a process of *knowledge to action* (KTA). This process has two broad stages: 1) knowledge creation and 2) action, each of which are made up of a series of smaller steps (Graham, et al., 2006). The knowledge to action process is represented diagrammatically in Figure 3.3, and described below.

### 3.6.4 Stage 1: Knowledge creation

K*nowledge creation* is depicted as a funnel shape, representing knowledge inquiry (i.e. research) (Figure 3.3). In any subject area, the complete body of knowledge is usually too broad, scattered, unwieldy and even contradictory to immediately and accurately answer a specific practice related question (Grimshaw, et al., 2012). Graham eloquently likened this first level of knowledge to: *"diamonds in the rough*" (p.18). Distillation of knowledge into pertinent, clear and useful elements is a crucial first step. Synthesis is the "basic unit of knowledge translation" and helps make sense of relevant knowledge, by distilling it to answer in whole or part a research or

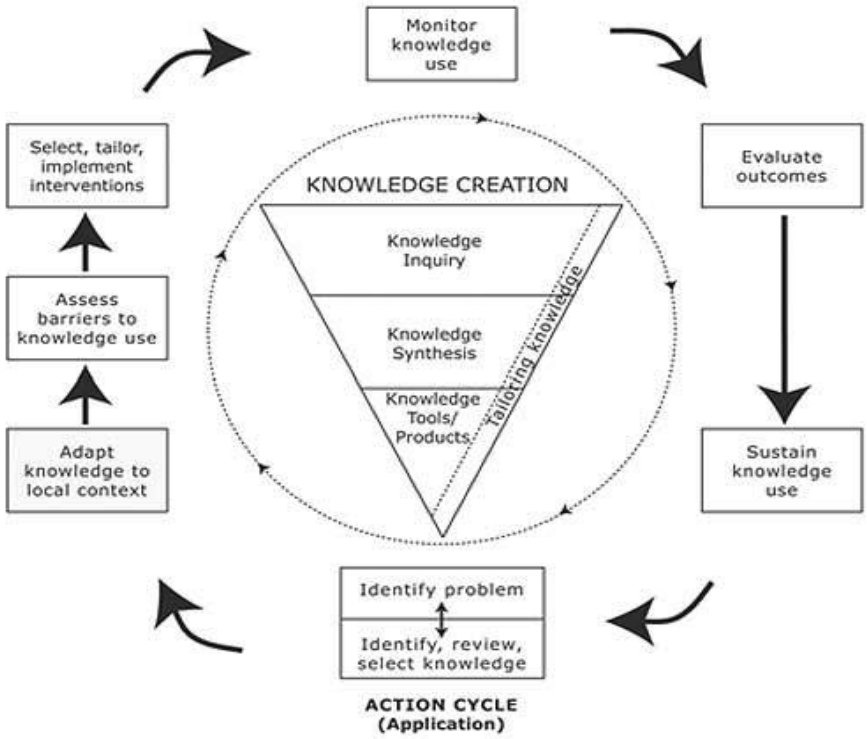


***Figure 3.2 The knowledge to action process***

Source: Figure reproduced with permission (Graham, et al., 2006)

clinical question (Grimshaw, et al., 2012). During this stage knowledge is tailored, with attention to its detail and fit with the research question, audience and manner of dissemination (Graham, et al., 2006). Once synthesised, the knowledge can then be distilled again into knowledge tools or products that give concise, key messages targeted to the people requiring the information, with the aim of helping policy makers, managers, clinicians, patients and their families make decisions about health care (Brouwers, Stacey, & O'Connor, 2010).

### 3.6.5 Stage 2: Action

The second part of the knowledge to action process is *action*, represented as a cycle of activities to implement knowledge (Graham, et al., 2006). These activities include both research and/or quality improvement projects. The first activity is identifying (or confirming) the problem or evidence-practice gap. Followed by determining the knowledge that will be required to address the gap and tailoring it to those within the local setting. The next activity is methodically assessing barriers to knowledge use, which in practice includes assessment of enablers. This step enables those seeking change to address barriers and harness enablers before and during the implementation of the intervention, to increase the likelihood of a successful undertaking.

Once implementation is underway, knowledge use is monitored. Changes in knowledge use can be measured as: i) attitudes and/or knowledge; ii) behaviour or practice; iii) power or profit (Graham, et al., 2006). Monitoring knowledge use allows for any necessary changes to be made to the intervention or implementation strategy. Outcomes can be evaluated at the patient, clinician and system levels, to establish whether or not the knowledge to action project was actually successful. Sustaining knowledge use is supported by cyclical use of the process (Graham, et al., 2006).

Knowledge translation activities may occur sequentially or simultaneously, and some may incorporate more than one component of knowledge to action. Not all activities may be required, applied in practice and/or reported within a knowledge translation undertaking (Field, Booth, Ilott, & Gerrish, 2014). Knowledge translation researchers may legitimately use additional theories and methods, such as those focused specifically upon team change, collaboration, education and quality improvement (Grol, Bosch, Hulscher, Eccles, & Wensing, 2007; Wensing, 2010).

## 3.7 The DePAC project studies and data collection methods

The DePAC project was composed of five studies that used a range of data collection methods:

- A systematic review (Study one) (Hosie, et al., 2013)

- An environmental scan incorporating i) a series of key informant structured interviews; and ii) a continuous snowball search of delirium knowledge tools (Study two)
- A prospective 24-hour cross sectional study (Study three)
- Face-to face and telephone interviews using the Critical Incident Technique and a clinical vignette (Study four) (Hosie, Agar, Lobb, Davidson, & Phillips, 2014; Hosie, Lobb, Agar, Davidson, & Phillips, 2014)
- A series of focus groups (Study five) (Hosie et al., 2015)

The systematic review methodology of Study one is reported in Chapter two. The remaining study methods and how they were employed within the DePAC project are described below.

### 3.7.1 Study two: Environmental Scan

Study two applied environmental scanning methodology to explore the integration of delirium knowledge tools within the systems of three specialist palliative care inpatient units in Sydney, Australia. In this study delirium knowledge tools were: i) clinical practice guidelines or pathways; ii) tools designed to screen, assess and/or confirm delirium and cognitive impairment; and iii) information resources for patients and families, such as brochures and decision aids.

Environmental scanning is a method of collecting external and internal information so that an organisation can better plan for future action and change (Chun, 2001). Originating from the business sector, it is a useful and flexible method to assess and design health services and interventions (Rowel, Moore, Nowrojee, Memiah, & Bronner, 2005). 'Scanning' the environment helps to identify areas requiring development within an organisation and available resources that support ongoing evolution (Legare et al., 2010)

Because the method of an environmental scan is relatively recent in health research it has not yet been definitively defined within the literature. The method has however been characterised as an investigative process that allows examination of a range of issues from a variety of sources, including information from informed and progressive thinkers, situated both within and without the profession and/or setting (Rowel, et al., 2005). A range of data collection methods can be used, such as

surveys, questionnaires, focus groups and/or interviews with key informants or stakeholders (Legare, et al., 2010). Peer-reviewed and grey literature, guidelines, media and policy may also be reviewed. Data collection methods can be formal or informal (e.g. review of guidelines vs personal communications) and use high or low technology (e.g. internet databases vs talking with key informants). More often than not, a combination of methods is required to collect and analyse all information relevant to the organisational investigation (Rowel, et al., 2005).

*Structured interviews with key informants*

Consistent with the combination approach to environmental inquiry, Study two used two different methods to collect data. The first data collection method was via a series of structured interviews with key informants, who were specialist palliative care clinicians (physicians, nurses and allied health professionals), educators and managers considered capable of providing rich insights and detailed information about the systems within their service. Data were obtained from these key informants via face-to-face group interviews that were guided by a structured questionnaire (Appendix 3). The questionnaire was a modified version of an existing Palliative Care Service Self-Assessment tool (Evaluation Tool 3.1) (Eagar et al., 2003), adapted to capture information about these palliative care units' service-level actions ('systems') relevant to delirium recognition and assessment. System-level actions were categorised within this questionnaire as: policy and procedure, routine use of tools, quality improvement and research projects, admission and discharge processes, and delirium occurrence measurement. If a system was identified as absent or ineffective, participants' were asked to rate the priority for its future development.

*Snowball search of delirium knowledge tools*

The second data collection method within the environmental scan was a continuous, non-systematic *snowball search* of delirium knowledge tools. The snowball technique is "…a continuous, recursive process of gathering, searching, scanning and aggregating references" (HLWIKI International, 2015). The search for delirium knowledge tools began in 2011 by the researcher reviewing recommendations, resources and references of the then three most current evidence-based delirium guidelines: i) *Clinical Practice Guidelines for the Management of Delirium in Older People* (Clinical Epidemiology and Health Service Evaluation Unit Melbourne

Health, 2006); ii) *Delirium: diagnosis, prevention and management, NICE Clinical Guideline 103* (National Clinical Guideline Centre for Acute and Chronic Conditions, 2010); and iii) *Guideline on the Assessment and Treatment of Delirium in Older Adults at the End of Life (Canadian Coalition for Seniors' Mental Health, 2010)* Using 'delirium' as the search term, the National Guideline Clearinghouse was searched for additional guidelines, (U.S. Department of Health and Human Services), as was the NSW Government Health website (NSW Government) and the CareSearch 'grey literature' filter searched for materials from government departments, palliative care organisations and outputs generated by the Australian Government funded National Palliative Care Projects (Australian Government Department of Health, 2014; Flinders University of South Australia, 2012). The snowballing search also incorporated knowledge tools sourced through the systematic search conducted in Study one (Hosie, et al., 2013). This iterative approach to searching continued until mid-2015, enabling a continuous building of an anthology of delirium knowledge tools throughout the duration of the DePAC project.

Data obtained from the key informant interviews and search for delirium knowledge tools were finally compared and contrasted to ascertain the extent of integration of delirium knowledge within the systems of the three participating palliative care units.

### 3.7.2 Study three: Cross sectional method

Study three used a prospective, cross sectional study method to estimate the 24-hour point-prevalence of delirium in an Australian palliative care inpatient population. A secondary aim of this study was to test the feasibility and acceptability of the methodology, given the challenges of ascertaining delirium for both research and clinical purposes in this population (Hosie, et al., 2013; Lawlor et al., 2014).

A cross-sectional study is an epidemiological research method, which observes, measures and describes the prevalence and characteristics of a health condition in a population at one point in time (Bonita, Beaglehole, & Kjellstrom, 2006). Cross sectional studies are sometimes described as a *snapshot* of the particular health care needs of a population, that enables health care planning (Bonita, et al., 2006). A health condition may be measured prospectively (occurring in the present) or retrospectively (occurring in the past) (Greenhalgh, 2010). A *point-prevalence* study measures at one point in time, while a *period-prevalence* study measures during a

period of time. An observational cross-sectional method differs from analytical epidemiology, which endeavors to demonstrate particular associations between the condition and another characteristic or exposure (Davis et al., 2013; Vandenbroucke et al., 2007). It may not be possible to definitively establish causation or outcomes of a condition when these are measured at the same point in time. Nor do point-prevalence studies capture which patients have *prevalent* delirium (present on admission) compared to *incident* delirium (newly occurring since admission) (Bonita, et al., 2006).

In Study three, a three-step process was used to screen, assess and diagnose delirium, using the: i) Nursing Delirium Screening Scale (Nu-DESC) (Gaudreau, Gagnon, Harel, Tremblay, & Roy, 2005); ii) MDAS (Breitbart et al., 1997); and iii) DSM-5 diagnostic criteria for delirium (American Psychiatric Association, 2013) (Appendices 1.2 and 1.3). Because the five-item Nu-DESC captures nurses' observations of patients around the 24-hour period, and is brief and observational, it was anticipated its use would promote inclusion of the majority of inpatients. The 10-item MDAS was chosen because it measures delirium severity, informs diagnosis, and has been used effectively in other studies of delirium in palliative care (Agar, et al., 2015; Lawlor et al., 2000). At the end of each 24-hour period, physicians used all available clinical information to determine if criterion A-E of the DSM-5 diagnostic criteria for delirium applied to each patient who had screened positive for delirium (Neufeld et al., 2014).

Study measures were undertaken at two palliative care units for 24-hour periods. The researcher collected patient demographics, diagnosis, functional status, palliative care phase, Nu-DESC, MDAS and DSM-5 status during each observation day, using a prospective audit method (Appendix 3). Data were analysed using descriptive statistics.

As for Study one, the reporting of this study was guided by Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines (Vandenbroucke, et al., 2007).

### 3.7.3 Study four: Critical Incident Technique Interviews with Vignette

Study four aimed to identify nurses' delirium assessment experiences, perceptions and capabilities and the facilitators and barriers to routinely recognising delirium in

palliative care inpatients. Face-to-face or telephone participant interviews were used to collected data in accordance with the Critical Incident Technique (Hosie, Agar, et al., 2014; Hosie, Lobb, et al., 2014).

*Critical Incident Technique*

The Critical Incident Technique is a qualitative research method focused on determining solutions for practical problems (Flanagan, 1954; Kemppainen, 2000). Detailed information about the way people with expertise in a particular area approach an activity or situation is obtained and meaning is interpreted with the intent of refining or progressing the behaviour or practice (Keatinge, 2002; Kemppainen, 2000). Critical Incident Technique was used in Study four to explore Australian palliative care unit nurses' delirium recognition and assessment experiences, perceptions and capabilities. This method was congruent with the aim of the DePaC project, as it enabled the researcher to explore nurses' delirium recognition and assessment practices and interpret the data with an ultimate focus upon how practice could be progressed (Butterfield, Borgen, Amundson, & Maglio, 2005).

Critical Incident Technique was developed by John Flanagan within the Aviation Psychology Program of the United States Army Air Forces in World War II, as a method of analysing what led to success or failure in aviation training (Flanagan, 1954). Flanagan described the Critical Incident Technique as:

> *… a set of procedures for collecting direct observations of human behaviour in such a way as to facilitate their potential usefulness in solving practical problems and developing broad psychological principles. The critical incident technique outlines procedures for collecting observed incidents having special significance and meeting systematically defined criteria (Flanagan, 1954, p. 1).*

Since this time, Critical Incident Technique has been used in many fields of professional practice, including design of equipment and job performance criteria, training, health care, nursing, counselling and community development (Flanagan, 1954; Hettlage & Steinlin, 2006; Schluter, Seaton, & Chaboyer, 2008). Originally an observational method, it is now more often applied by asking research participants to recall and recount their experiences of previous situations, relevant to the area of

inquiry (Bradbury-Jones & Tranter, 2008). Asking for anecdotes enables participants to tell their stories and share their insights about people and real events (Bradley, 1992). Observations become 'facts' when several independent participants offer the same descriptions of behaviour related to the situation or incident. Participants' descriptions must include three elements: i) what was happening in the lead up to the incident; ii) the actions of the person/persons during the incident; and iii) the outcomes of the actions, as it is only when all three are present that the researcher can determine the effectiveness or otherwise of the described actions (Butterfield, et al., 2005). Incidents, rather than participants, are the units of analysis.

Advantages of the Critical Incident Technique are its flexibility, brevity of interviews, appeal of storytelling for people, and potential to generate positive change. Critical Incident Technique was therefore a fitting, feasible and powerful method to draw out practical and tacit knowledge of palliative care nurses in delirium recognition and assessment, and tap into past clinical events that may have a lingering effect on nurses and their practice (Butterfield, et al., 2005; Keatinge, 2002).

Limitations arise from the flexibility of applying Critical Incident Technique, which has resulted in inconsistencies in the application of its methods, primarily the inclusion of data that do not meet the three elements that together constitute an 'incident' (Bradbury-Jones & Tranter, 2008). The words 'critical' or 'incident' may be misleading, especially for participants working in health care where these words are associated with emergency medical situations and/or adverse events, that may have arisen from staff error and/or led to formal complaints (Schluter, et al., 2008). To reduce the potential for this misunderstanding and make clear to participants the focus of the study, a clinical vignette of a palliative care inpatient with unrecognised hypoactive delirium was developed and used to initiate the interviews, as described below.

*Development and use of a clinical vignette*

Vignettes are brief descriptions of clinical situations, upon which questions relating to clinical practice can be based (Mc Crow, Beattie, Sullivan, & Fick, 2013). Because a clinical scenario within a vignette can be designed, standardised and controlled according to the intent of an educator or researcher, they are an effective

and consistent means to explore or test respondents' knowledge and/or decision-making within a specific area of focus (Mc Crow, et al., 2013; Peabody, Luck, Glassman, Dresselhaus, & Lee, 2000; Veloski, Tai, Evans, & Nash, 2005). The use of a vignette also mitigates the need for the required scenario to occur in clinical practice. This is especially advantageous when the scenario relates to a rare, difficult to recognise, sudden, sensitive and/or serious patient situation. Similar to the Critical Incident Technique, vignettes offer a more feasible, ethically acceptable and economical research strategy to examine health care practices than ethnographic or observational methods. Vignettes have been successfully used in studies measuring nurse recognition of delirium superimposed on dementia (Fick, Hodo, Lawrence, & Inouye, 2007), the impact of a web-based delirium educational intervention for nurses (Mc Crow, Sullivan, & Beattie, 2014) and health professional approaches to other problems such as depression (Buist, 2005).

Given the prior evidence that nurses across care settings do not fully understand or recognise delirium (Agar et al., 2012; Steis & Fick, 2008), it was anticipated that the use of a vignette was a necessary complement to the Critical Incident Technique within Study four. Moreover, the intent was not just to prompt participants to recall delirium, but recall the *under-recognition of delirium,* especially the hypoactive subtype. Consequently, the vignette was designed with this intent, and also to be familar and comprehensible to all participants, regardless of the extent of their delirium knowledge. Using a vignette was considered more effective than merely asking participants to recall and recount 'a critical incident of a patient experiencing delirium' (Schluter, et al., 2008). A recall approach may have biased participants towards remembering patients with hyperactive delirium, which presents more dramatically, is more distressing for nurses to witness, and therefore more memorable (Breitbart, Gibson, & Tremblay, 2002).

The vignette was based upon an actual patient experience that was relayed to the researcher by a nurse colleague. Information about the patient's experience was developed to contain sufficient detail about the features of hypoactive delirium, based upon the DSM-IV-TR criteria for delirium (American Psychiatric Association, 2000) and delirium phenomenology literature (Gupta, de Jonghe, Schieveld, Leonard, & Meagher, 2008; Meagher et al., 2011). The supervisory team [PD, MA, EL, JP], had clinical and research expertise in delirium and/or palliative care, and

assessed the construct validity of the vignette. Minor changes were made, to remove palliative care jargon and simplify the vignette. Vignette clarity and face validity were confirmed through pilot interviews with four nurses from two palliative care units who had differing levels of clinical experience.

*Face-to-face and telephone interviews*

During Critical Incident Technique interviews, the role of the researcher is to ensure brief, straightforward questions, establishment of rapport, and that participants are assisted to provide specific and detailed descriptions (Schluter, et al., 2008). To achieve this, the interviewer firstly must themselves have expertise and insight into the activity being researched. Secondly, notwithstanding his or her prior insights, the interviewer should ask open-ended or probing questions of participants, to elicit the exact 'what' and 'why for' within the recounts. Thirdly, by conducting interviews in a supportive manner, so that participants feel safe to disclose incidents that may be difficult to share, due to either the nature of the clinical situation or outcomes which were not ideal (Schluter, et al., 2008). The researcher must therefore achieve a balance between insight, objectivity and sensitivity, as they listen to participants' recounts and elicit more detail from them, as required.

Despite the very focused and brief nature of Critical Incident Technique interviews, they correspond with the essential qualities of effective research interviewing, which include interest in the experiences and views of participants, demonstration of respect, sincerity and authenticity, and achieving a balance between listening, probing and managing the interview process (Liamputtong & Ezzy, 2005b). Other important considerations included ensuring participants' privacy, confidentiality and comfort during the interview, and that the environment was free of distractions, interruptions and background noise to allow for engagement, focus and digital-recording (Serry & Liamputtong, 2010). Face-to-face interviews were therefore conducted within quiet, private rooms within each participating site. Telephone interviews were also employed to facilitate inclusion of nurses working across different geographical areas and in palliative care units situated in non-metropolitan regions. Telephone interviews are equally effective as a method of data collection, are acceptable to participants, and cost effective (Sturges, 2004).

### 3.7.4 Study five: Focus Groups

Study five was designed to explore nurses' perceptions of the feasibility of integrating the Nursing Delirium Scale into clinical practice through a series of focus groups. Focus groups are a qualitative research method that encourage and capitalise upon open and lively interactions within a group of participants, to gather both individual and collective opinions (Davidson, Halcomb, & Gholizadeh, 2013). If an ideal atmosphere of informality, ease and safety is achieved during focus group conversations (which is dependent upon the skill of the facilitator, the topic and group dynamics) participants are more likely to spontaneously discuss areas of commonality and shared experiences, and freely dispute, debate and disagree with each other (Liamputtong & Ezzy, 2005a). This synergy can result in richer, more varied and unexpected data than what might be obtained using a one-on-one interview data collection method (Liamputtong & Ezzy, 2005a).

Challenges of focus groups include the unpredictability of the interactions that can occur when working with groups of people. The facilitator must be prepared to effectively manage conflict if it arises, skilfully and respectfully lead off-track discussions back onto topic, and ensure well-being of all participants, without disrupting the flow of relevant discussion. They must also be able to stimulate participants to engage in a conversation about the given topic, particularly those who are less talkative or become subdued by more authoritative group members (Davidson, et al., 2013). Further attributes of an effective focus group facilitator include having knowledge of the project, being open-minded, flexible and a good leader, listener and observer of people (Liamputtong & Ezzy, 2005a). Other challenges relate to ensuring the confidentiality of participants, given that other participants are privy to the information revealed.

In research related to patient care, obtaining the collective viewpoint of nurses can reveal much about the prevailing attitudes to a specific area of practice (Davidson, et al., 2013). A focus group method was used in Study five, to explore nurses' perceptions of the feasibility of integrating the Nu-DESC into routine practice within the inpatient palliative care setting (Hosie, et al., 2015). It was anticipated focus groups would promote conversation and interaction between participating nurses about their experiences and perceptions of using the Nu-DESC and follow up care within the palliative care unit, and reveal both diversity and commonality of their

views. Focus groups also provided a feasible and efficient way for the researcher to rapidly and economically obtain the insights of several nurses (Davidson, et al., 2013).

There were two facilitators of the four focus groups conducted in Study five: an on-site research nurse (who was experienced in conducting focus groups) and the researcher, who had experience in conducting one-on-one interviews but was new to the focus group method. Each separately undertook two focus groups at the two sites. To promote consistency of approach, the brief semi-structured question route was integrated into a focus group schedule and field note form. The focus group schedule contained an introductory script that reiterated the purpose of the study, voluntary nature of participation, and need to maintain confidentiality and respect for others' opinions. The two facilitators discussed the planned approach prior to data collection, each used the focus group schedule and field note form to guide discussions, and the first facilitator discussed her impressions and emailed transcriptions to the researcher on the day of completion of Site 1 focus groups (Hosie, et al., 2015).

Studies four and five were exploratory studies employing qualitative methods, and their reporting was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong, Sainsbury, & Craig, 2007).

### 3.7.5 Positioning the DePAC studies within the knowledge-to-action process

The DePAC project's alignment with the knowledge-to-action process is described, and represented diagrammatically in Figure 3.4, below.

Within the DePAC project, the *knowledge creation* stage involved the systematic review of delirium prevalence and incidence in palliative care inpatient units, reported in Chapter two (Hosie, et al., 2013); and the identification and summation of delirium knowledge tools component of the environmental scan, as reported in Chapter four.

The *action* stage began with an examination of the point-prevalence of delirium in an Australian palliative care unit (Study three), to ascertain local delirium occurrence and confirm the need for change at the local level. Followed by an in-depth exploration of Australian palliative care nurses' delirium recognition and assessment experience, perceptions and capabilities, and of the barriers and enablers to their

delirium practice (Study 4) (Hosie, Agar, et al., 2014; Hosie, Lobb, et al., 2014). Study five (Hosie, et al., 2015) proceeded to explore nurses' perceptions of the use of one delirium screening tool, the Nu-DESC (Gaudreau, et al., 2005). This detailed assessment of the context, gaps and needs informs the next stage of the knowledge to action process, which will be the focus of the researcher's post-doctoral program of research (The DePAC project - Phase three) and will include: selection, tailoring and implementation of an intervention, monitoring knowledge use, measuring outcomes, and sustaining knowledge use.

## 3.8 Analysis of quantitative, qualitative and mixed methods data

Data analysis for each study conducted within the DePAC project is reported in detail within each Chapter, and can be broadly described as:

*Quantitative data* being analysed using descriptive statistics (Studies one and three).

*Qualitative data* being analysed descriptively (Study two) and using thematic content analysis (Studies four and five).

*Quantitative and qualitative (mixed methods) data* were integrated at the completion of the five studies to gain an overview of the DePAC project as a whole (Cameron, 2009). Development of the theoretical understanding through a *meta-inference*, was achieved using the complementarity model of triangulation (Cameron, 2009; Erzberger & Kelle, 2003). Meta-inference integrated the mixed methods DePAC data with the original understanding ('inference') that delirium knowledge needed to be translated into the systems and practices within palliative care inpatient units to improve recognition and assessment by nurses (Cameron, 2009). Meta-inference further developed theoretical understanding of the problem of delirium under-recognition in the palliative care inpatient setting.

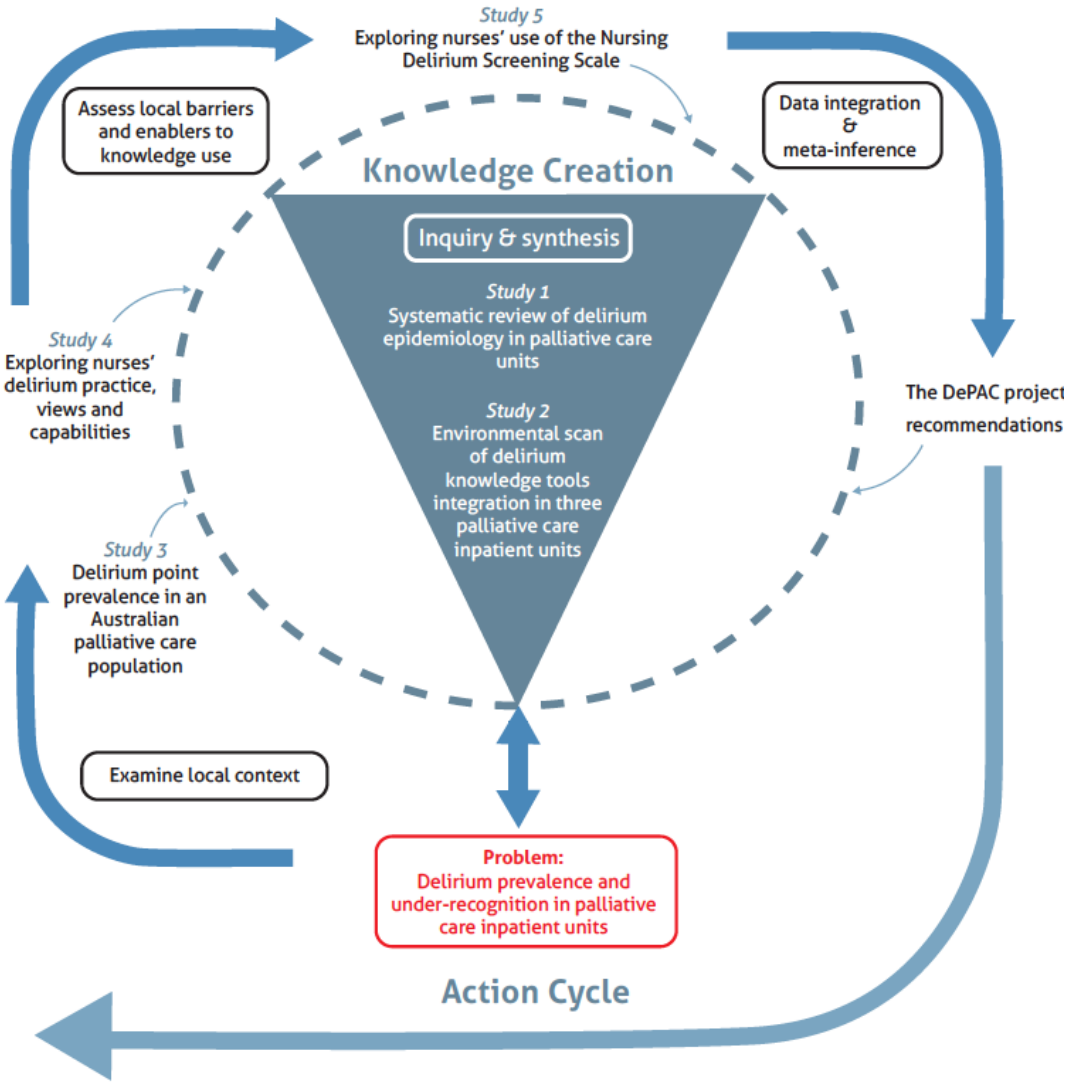


***Figure 3.3 Application of the knowledge to action process within the DePAC Project***

Adapted from: (Graham, et al., 2006)

## 3.9 Ethical considerations

### 3.9.1 Ethical approval

Ethical approval for the DePAC project was obtained from the St Vincent's Hospital Human Research Ethics Committee (HREC). The reference number for ethical approval of Studies two, three and five was: HREC/13/SVH/152. The reference number for Study four was: LNR/12/SVH/336. Ethical approval (reference number 012058S) and cross-institutional ratification (reference number 013111S) were obtained from the University of Notre Dame Australia research office. Site-specific governance approval was obtained for the researcher to undertake research at each participating palliative care units. Appendix 4 contains copies of ethical approval and cross-institutional ratification confirmation letters.

### 3.9.2 Considerations for patient participants

The DePAC project's ethical considerations for patient participants related primarily to: i) minimising the burden of study processes; and ii) waiver of patient consent to conduct delirium screening and collect de-identified data within Study three (National Health and Medical Research Council, 2007).

Ethical approval for waiver of written patient consent for delirium screening and assessment was sought and obtained in Study three (Agar, Ko, Sheehan, Chapman, & Currow, 2013). Undertaking screening was not beyond what could be routinely done in clinical practice, the Nu-DESC imposed no burden on patients, and it was important to obtain an accurate point-prevalence by not excluding delirious or dying patients, or those who were otherwise unable to provide verbal consent (Adamis, Martin, Treloar, & Macdonald, 2005; Agar, et al., 2013).

Patients and family were informed about the study via information posters that advised of the opt-out approach to delirium screening and assessment (Appendix 5), and the provision of brief, scripted verbal study information when approached by the researcher to complete the MDAS.

### 3.9.3 Considerations for clinician participants

Studies two, four and five involved participants who were clinicians, who are a less vulnerable research population than palliative care patients. Clinician participation in these exploratory studies was potentially empowering for them, with foreseen benefit from the opportunity to reflect on workplace systems and practice, share

stories, experiences and expertise, and create explicit knowledge from what may have previously been unspoken, embedded or taken for granted in practice (Hettlage & Steinlin, 2006).

It was also acknowledged that participants may reflect on previous challenging clinical situations with delirious patients, personal experiences of loved ones with delirium, and/or realisation of gaps between best practice and one's own knowledge, practice or workplace systems of care. The researcher was mindful it was possible participants might perceive the research process as critical of their clinical actions. To minimise these potential risks the researcher endeavoured to establish rapport with participants, ensure they felt supported and remain alert to signs of distress or discomfort. Support mechanisms were factored into study protocols. The researcher was available by telephone or email if participants wished to discuss any aspects of the study, and was prepared to refer participants back to their first-line managers if they experienced distress associated with delirium care, past or present.

Study participation by clinicians was voluntary and involved an informed and written consent process (see Appendix 5).

### 3.9.4 Data management and storage

All data arising from the DePAC project, including audiotapes, electronic and paper forms of transcripts, signed participant consent forms, chart audits and participant logs, were stored securely on the researcher's password-protected computer and/or in a locked filing cabinet in a secure office within The Cunningham Centre at the Sacred Heart Palliative Care Service, Darlinghurst, Sydney, Australia. Confidentiality and privacy were maintained through assignation of participant and site codes; storing of signed consent forms and participant logs separately from other study data; and removal of all names within transcripts. Publications contain de-identified data. Data are accessible only by the investigators or relevant research personnel, and stored within a secure office within The Cunningham Centre at the Sacred Heart Palliative Care Service, Darlinghurst. Data will be stored here for a period of 5 years from the date of any associated publications (National Health & Medical Research Council & the Australian Research Council & Universities Australia, 2007). All data will be destroyed after this time, using the processes required for destruction of confidential patient information.

## 3.10 Conclusion

This chapter has outlined the mixed methods design and processes, knowledge translation conceptual framework and data collection methods of the DePAC project. Varying study designs and data collection methods were used within this project to enable each of the research questions to be answered.

Chapter four reports an environmental scan that mapped the integration of delirium knowledge tools within the systems of three Australian specialist inpatient palliative care units.

## 3.11 References

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# Chapter 4: The integration of delirium knowledge in palliative care inpatient units: an environmental scan

## 4.1 Chapter preface

Chapter three outlined the mixed methods approach, knowledge translation conceptual framework and data collection methods of the DePAC project. Chapter four continues to scope the problem of delirium under-recognition and assessment in palliative care inpatient settings. The environmental scan reported in this Chapter moves the knowledge translation process forward by 'mapping' the integration of synthesised delirium knowledge (*knowledge tools)* within three inpatient palliative care units. This study addresses the following research questions:

i) Is delirium recognition and assessment guidance available to nurses working in palliative care inpatient settings?

ii) What are the barriers and enablers to nurses' recognising and assessing delirium in palliative care inpatient settings?

## 4.2 Introduction

As outlined in Chapter one, specialist palliative care in Australia is delivered by multidisciplinary teams comprised of varying disciplines, including medical, nursing, allied health, pastoral care and volunteers (Palliative Care Australia, 2005). Numerous organisational or 'system' level factors influence the way these teams provide care, such as: team configuration and interactions, the availability of evidence and resources; hospital and unit culture; and organisational supports like policy, capable leadership and quality assurance processes (Flottorp et al., 2013). Palliative care units and their associated hospitals all function within the wider health care, academic, social, religious, legal, economic and political environments (Legare et al., 2011; Reid, Compton, Grossman, & Fanjiang, 2005). These environmental influences impact on clinicians' access to resources and shape the delirium care provided to inpatients (Adams et al., 2015). Nurses' uptake of delirium knowledge is central to the provision of optimal inpatient delirium care (Balas et al., 2012).

An exploration of the availability of synthesised delirium knowledge and its integration into the organisational systems of Australian palliative care inpatients

units has not previously been conducted. As delirium knowledge tools provide evidence-based guidance to help managers, clinicians, patients and families make informed decisions about health care, a study of the extent of their integration within inpatient palliative care units and the resultant implications for nurses' capabilities to recognise and assess their patients' delirium is warranted (Brouwers, Stacey, & O'Connor, 2010).

## 4.3 Aims

The aims of this study are to:

Identify and describe the suite of knowledge tools designed to assist with delirium recognition and assessment in adult inpatient populations; and

Determine the extent to which these delirium knowledge tools have been integrated within three palliative care inpatient settings in Sydney, Australia.

## 4.4 Methods

### 4.4.1 Design

This study used an environmental scanning methodology incorporating: i) structured key informant interviews; and ii) a snowball literature search of available delirium knowledge tools.

### 4.4.2 Setting and participants

Data relating to the delirium recognition and assessment systems within three palliative care inpatient units in Sydney, Australia were obtained from key informants, who were: specialist palliative care clinicians (physicians, nurses, and allied health professionals), educators and managers employed at the participating sites.

### 4.4.3 Recruitment and informed consent process

Designated study investigators at each site (medical directors (n=2) and a research department manager) nominated the key informants working within their respective palliative care services. The researcher emailed an invitation to participate and the participant information and consent form to the nominated key informants (Appendix 5). The key informants were given the opportunity to ask questions and discuss the implications of participation. Participation was voluntary, with no negative

consequences for non-participation. Written consent was obtained from participants immediately prior to the interviews.

### 4.4.4 Data collection

As described in Chapter three, environmental scan data were obtained from key informants via face-to-face group interviews guided by a structured questionnaire (Appendix 3). Data pertaining to delirium knowledge tools were obtained through a continuous non-systematic snowball search of the peer-reviewed and grey literature (2011-2015) (Contandriopoulos, Lemire, Denis, & Tremblay, 2010; HLWIKI International, 2015).

### 4.4.5 Inclusion criteria for delirium knowledge tools

*Delirium Guidelines:* were included if they were first published in English between 2005 and 2015 and related to delirium care of palliative, geriatric (aged $\geq$ 65 years), Intensive Care Unit (ICU), and/or inpatient acute general hospital populations. Guidelines relevant to inpatient populations outside of specialist palliative care, such as geriatric, critical care and acute care, were considered to be a potential rich source of relevant delirium knowledge because they have similar demographic, delirium challenges and/or end-of-life care needs (Ahmed, Leurent, & Sampson, 2014; ICU Delirium and Cognitive Impairment Group, 2013).

*Delirium and cognition measurement tools:* were included in the environmental scan if they were recommended within the included guidelines or identified by key informants as being available for use and/or promoted within their palliative care units.

*Patient and family resources*: were included if they provided information about delirium and were relevant to the inpatient care setting.

### 4.4.6 Data synthesis and analysis

Data obtained from key informants during the structured interviews were analysed descriptively under the following predefined categories: i) awareness and assessment of patient's delirium risk; ii) delirium screening; iii) delirium diagnosis and/or confirmation; and iv) comprehensive delirium assessment.

Guidelines meeting the inclusion criteria were examined for delirium recognition and assessment recommendations. Relevant recommendations were tabulated and/or

described according to the categories listed above. Where available, levels of evidence for clinical guideline recommendations were provided within the data summary tables; however, the quality of included delirium knowledge tools was not systematically appraised.

Data relevant to delirium care obtained from key informants and guidelines were integrated to better understand the practices that were occurring in each of the specialist palliative care units in terms of their processes for: managing early routine identification of delirium, establishing and confirming a delirium diagnosis and ensuring ongoing comprehensive delirium assessment. The existing systems of patient care within the three participating palliative care units were compared and contrasted ('mapped') against the identified delirium knowledge tools recommendations and availability. The iterative mapping process integrated the data to form a more comprehensive understanding of the degree to which the delirium evidence had been embedded into routine clinical practice.

## 4.5 Findings

The findings of this environmental scan are reported as A: Key informant interviews; B: Delirium knowledge tools; and C: Mapping palliative care unit delirium recognition and assessment systems against the identified knowledge tools.

### 4.5.1 Part A: Key informant interviews

Interviews were conducted with key informants (n=14) during November 2013. All invited key informants participated, with the exception of one Nursing Unit Manager who had a prior commitment. Participants were: managers (n=4); medical directors (n=3); Clinical Nurse Consultants (n=2); Clinical Nurse Educators (n=2); a palliative care staff specialist, a social worker and a physiotherapist. The majority of the interviews were group interviews (n=3), while one participant (a Clinical Nurse Educator), who was unable to attend but keen to contribute, arranged a time to have a one-on-one interview with the researcher.

All of the interviews (face-to-face group and individual) were each around one hour's duration and held in an on-site meeting room that allowed for confidential and uninterrupted discussions. The researcher facilitated the group interviews, structured the discussions according to the items of the questionnaire (Appendix 3), completed

the questionnaire items and made extensive notes during and after the ensuing discussions, including verbatim quotes. Interviews were not audiotaped.

Undertaking the group interviews revealed that, while the questionnaire structure and items about: policy and procedure, routine use of tools, quality improvement and research projects, admission and discharge processes, and delirium occurrence measurement (Appendix 3) were useful guides for discussion, achieving a numerical ranking consensus for prioritising of systems was not a workable strategy. A more qualitative approach was instead adopted, because at times there were divergent opinions about the priority of particular systems for delirium recognition and assessment. This qualitative approach allowed the researcher to more accurately note, consider and interpret the participants' varying perceptions about the priority of system change to improve delirium care.

During the interviews, each group volunteered to share their unit's admission forms with the researcher. Access to these admission forms enabled the researcher to conduct a more detailed examination of the extent to which patients' delirium and/or cognitive status were evaluated at the time of admission.

The findings arising from the interviews with key informants are described below:

*Awareness and assessment of patient risk of delirium*

Participants generally acknowledged that palliative care inpatients are at risk of delirium and were aware of its association with palliative care interventions for other distressing symptoms common in life-limiting illness. Despite this acknowledged risk, patients' were not formally assessed for delirium on admission to any of the units.

There was general consensus of the need to improve delirium recognition and assessment within inpatient specialist palliative care units. In addition to the delirium RCT mentioned in Chapter three (Agar, 2010), two of the sites were involved in further delirium research, including: a pilot delirium prevention RCT (Agar, 2012); a pharmaco-vigilance study of haloperidol for delirium (Crawford et al., 2013); an observational study of the relationship between anxiety, depression and delirium; a pilot evaluation of the Clock Drawing Test (CDT) as a delirium screening tool (Sunderland et al., 1989); and exploration of family experience of delirium. One site was undertaking two additional delirium related quality improvement projects: i)

development of 'flip charts' to guide delirium interventions during team meetings; and ii) falls prevention. These research and quality improvement activities being undertaken in two of the three sites indicated that there was a high level of awareness of delirium, and an appreciation of the need to develop local evidence and practice for delirium within palliative care.

### 4.5.2 Screening for delirium and cognitive impairment

Yet awareness and research and quality improvement activity had not translated into routine screening of palliative care patients for delirium or cognitive impairment. Sporadic and/or non-specific processes were used within the three units to recognise delirium or other cognitive impairment. Five different delirium and cognition tools were available across these three units, but despite their availability none were routinely completed. The tools were: i) MMSE (Folstein, Folstein, & Mc Hugh, 1975); ii) Nu-DESC (Gaudreau, Gagnon, Harel, Tremblay, & Roy, 2005); iii) CDT (Sunderland et al., 1989); iv) Rowland Universal Dementia Assessment Scale (RUDAS) (Storey, Rowland, Basic, Conforti, & Dickson, 2004); and v) MDAS (Breitbart et al., 1997) (Appendix 1.3). While the MDAS was available at all three units, it was only used for research purposes (Agar, 2010).

*On admission:* One unit routinely screened patients for delirium for the first three days of admission, using three tools: the MMSE, in conjunction with the Nu-DESC (nursing) and the CDT (medical). Despite these three tools having been formally implemented within the admission process, the MMSE was rarely completed and the Nu-DESC and CDT not consistently so. During the key informant discussion the site's Nursing Unit Manager asked: "*What is the purpose of the Nu-DESC*?" and stated that *"nursing observation skills"* were sufficient to recognise when patients were delirious. No validated delirium tools were used on admission to the other two units. Instead, locally developed admission forms were used, containing variously termed 'tick boxes' to document patients' level of alertness and orientation. A medical admission form listed 21 'palliative care problems', which did not specifically include delirium. Another multidisciplinary admission form contained a blank section to document 'cognitive deficits', plus a checklist of 19 symptoms, of which: 'insomnia', 'lethargy' and 'fatigue', which are suggestive of the presence of delirium; however, delirium as a single entity was not specifically listed.

*During admission:* Throughout an admission patients' cognitive abilities were tested at clinicians' discretion, using either the RUDAS (n=3 units); MMSE (n=2 units) or the CDT (n=2 units). Nurses were not responsible for administering these tools, with cognitive testing being initiated by medical, occupational therapy and physiotherapy staff in specific circumstances. Occupational therapists undertook cognitive testing within broader functional assessment of referred patients only. Physiotherapists occasionally assessed patients' cognition to ascertain their capacity to consent to physiotherapy. In one unit, structured cognitive assessment by in situ or consultative medical staff was reserved for patients believed to have a complex psychiatric condition, other than delirium. In two units, testing of patients' cognition by medical or allied health clinicians primarily occurred during discharge planning, when considering the most appropriate place for ongoing care (i.e. private home, aged care facility or continuing care in the inpatient unit). Participants reported that delirium and other cognitive impairment delayed patients' discharge.

*Training in use of tools:* Clinical trials nurses at all of the sites had provided bedside nurses with intermittent didactic and one-on-one training in use of the Nu-DESC, for research purposes (Agar, 2010). At one site, the Clinical Nurse Educator had conducted additional in-service education for nurses about delirium and use of the Nu-DESC; while senior physicians had developed a delirium management manual for junior physicians, including how to administer the CDT and MDAS.

*Organisational ratification:* Two sites had experienced difficulty obtaining organisational approval to implement new delirium screening tools. At one site, the 'forms committee' had not ratified the use of the Nu-DESC, primarily because of the need to manage the multiplicity of forms across the whole hospital setting.

### 4.5.3 Confirmation of delirium

No sites used any tool to confirm delirium, such as the CAM or its variants. Physicians were responsible for assigning patients a diagnosis of delirium, yet it was unclear how this was determined in practice, as no readily accessible or visible information about the DSM-V or IV diagnostic criteria for delirium was present in any of the units.

### 4.5.4 Comprehensive assessment of delirious patients

With the exception of the delirium management protocol for junior physicians, no unit had point-of-care guidance for comprehensive assessment of delirious patients. Most participants believed delirium guidance, policy and/or pathways were important, but that to develop these at the unit level was considered to be "…*in the too hard basket"*. Some participants believed variation in delirium care practices across the whole hospital setting was another barrier to developing guidance specifically for the palliative care unit. They were also concerned that practice implemented according to delirium guidelines may be too prescriptive and stymie clinicians' autonomy and critical thinking about the most appropriate interventions for individual patients.

One participant spoke of how many palliative inpatients were now more "…*acute, having chemotherapy or radiotherapy or symptom control*", rather than being in the last days of life. This nurse participant suggested that the increased acuity amplified the complexity of the assessment process. Participants believed assessment should be both structured and individualised, and include consideration of individual needs and wishes of the patient, i.e. "*where patients are at*".

Several participants (physicians at two sites and a nurse at another) highlighted the need for improved assessment of agitated patients, especially for patients in the terminal phase and/or those unable to vocalise. These participants' expressed concern that nurses often administered benzodiazepines such as midazolam (commonly prescribed on an 'as required' basis for all patients at two sites) when patients were agitated, prior to a full assessment of the patient and definitive identification of the cause of the agitation. Participants' believed this practice more frequently occurred during the night, and that nurses' resorting to sedation as the first line of treatment for agitation was "*problematic*". In response to this inappropriate practice, one unit had ceased the practice of routinely prescribing PRN benzodiazepines for all patients and developed a protocol to guide appropriate administration of 'as required' medication for management of patients' symptoms.

### 4.5.5 Other identified gaps and opportunities for delirium care

Participants suggested that there were gaps in clinicians' delirium knowledge and competency. There was a perceived need for nurse education in delirium, starting with the "…*basics*…*what delirium is, how to screen, assess, communication, and*

*then what?"* In addition to building delirium capabilities it was acknowledged that systematic change was required to better support optimal delirium care and assist in overcoming complex learning challenges such as: "*Clinical reasoning - how do we teach that*?" Some participants identified the need to strengthen interdisciplinary teamwork and education, as all delirium assessment and education occurred within discipline specific silos and was not an integrated team approach. There was consensus that focused team discussions about each patient's delirium status should occur, but these 'delirium conversations' were generally "*just not there*". Participants at two sites suggested that discussions about patients' delirium or cognitive status sometimes took place during the scheduled weekly multidisciplinary team meetings. Ironically these discussions more often occurred when discharge was being planned as opposed to when the patient had delirium. The third site held multidisciplinary team meetings each weekday morning, which held potential for more frequent discussions about patients' delirium status, but these meetings were held in a room away from patients and family and not at the bedside.

Guidance about optimal routine approaches for communication with patients and family about delirium were absent at all sites. Some participants' expressed uncertainty about the best way to discuss delirium with patients and family. Two physicians had developed and memorised for their own use a short 'script' to explain delirium to others. There were suggestions that delirium information pamphlets might be a useful resource, and that future interventions to improve delirium care ought to involve the patient, their family and/or palliative care volunteers. No participants referred to using any existing delirium information resources for patients and family.

While palliative care services across Australia voluntarily collect daily symptom screening and problem scores as part of their participation in the Palliative Care Outcomes Collaborative (PCOC) (2014) screening for delirium is not part of this suite of key performance indicators. Consequently, the rate of delirium occurrence and patients' response to intervention across all units was not known. Some participants' believed that measuring delirium occurrence and patient response to intervention routinely was a priority; however, they also doubted delirium should be considered a key performance indicator, because of the lack of evidence that delirium is preventable in palliative care inpatient populations (Gagnon, Allard,

Gagnon, Merette, & Tardif, 2012; Lawlor et al., 2014). One Medical Director described the idea of using delirium occurrence as a key performance indicator as: *"setting up to fail"* and another physician as: *"a dangerous argument".*

Participants suggested delirium might be routinely screened using an existing tool, either: the PCOC tool, the Symptom Assessment Scale (SAS), a numerical rating scale of distress associated with common symptoms (Aoun, Monterosso, Kristjanson, & Mc Conigley, 2011; Kristjanson et al., 1999); or, via the mandatory '*NSW Between the Flags System*', which sets parameters for vital and neurological signs to prompt recognition and management of patients who are deteriorating (Clinical Excellence Commission, 2015a). Another suggestion was nurses' delirium observations could be included in the '***I**ntroduction, **S**ituation, **B**ackground, **A**ssessment, **R**ecommendation*' (ISBAR) bedside handover system, to improve communication of patients' delirium status between shifts (Clinical Excellence Commission, 2015b).

Nursing and medical participants wondered: "*What do we do once delirium is identified?*" Gaps in the evidence for effective management contributed to participants' uncertainty of the value of developing delirium screening and assessment systems for their unit. Conversely, participants acknowledged that effective management could not be achieved unless delirium was initially identified. Participants from one site wanted to first obtain local delirium prevalence data before committing to any changes to systems of care.

Participant s also described previous adaptation of their systems and routine practices in response to policy instigated at the wider hospital or NSW government health care level for related aspects of care, such as for restraint, falls and management of patient deterioration. During one discussion about the potential for similar higher-level policy to improve delirium care, one participant categorised delirium as *"a wicked problem*", meaning that positive changes to delirium care would indeed require examination and adaptation of the entire culture, systems and practice of the palliative care unit.

### 4.5.6 Part B: Delirium knowledge tools

The environmental scan identified ten clinical guidelines, multiple delirium (n=9) and cognition (n=7) tools and five information resources for patients and family relevant to delirium recognition and assessment.

*Delirium Guidelines*

The ten identified guidelines (Table 4.1) originated from five high-income countries: Australia (n=5), UK (n=2), US (n=1), Canada (n=1), and Switzerland (n=1). They varied in their target populations (older patients vs adult patients), settings (hospital, ICU, long-term residential care), audiences (health care managers, clinicians, consumers) and degree of inclusion of palliative care evidence and/or populations. These delirium guidelines also differed in their model, philosophy and goal, adopting (either implicitly or explicitly): biomedical, quality and safety, prevention of

***Table 4.1 Delirium Guidelines: Scope, evidence-base and approaches***

| Guideline | Prevention, diagnosis and management of delirium in older people in hospital (2006) | Management of Delirium in Older People (2006) | Delirium: Guidelines for general hospitals (2007) | Palliative Care Clinical Management Guidelines: Delirium (2009) | Therapeutic Guidelines Palliative Care (2010) | Assessment and Treatment of Delirium in Older Adults at the End of Life (2010) | Delirium: diagnosis, prevention and management (2010) | Management of Pain, Agitation, and Delirium in Adult Patients in the Intensive Care Unit (2013) | Key Principles for Care of Confused Hospitalised Older Persons (2014) | Safe and high-quality care for patients with cognitive impairment (dementia and delirium) in hospital (2015b) |
|---|---|---|---|---|---|---|---|---|---|---|
| **Developing body/authors** | Royal College of Physicians and British Geriatrics Society | Clinical Epidemiology and Health Service Evaluation Unit Melbourne Health | Delirium Guidelines Development Group | Department of Health and Human Services Tasmania | Palliative Care Expert Group | Canadian Coalition for Seniors' Mental Health | National Clinical Guideline Centre for Acute and Chronic Conditions | American College of Critical Care Medicine | NSW Agency for Clinical Innovation | Australian Commission on Quality and Safety of Healthcare |
| **Country** | UK | Australia | Switzerland | Australia | Australia | Canada | UK | US | Australia | Australia |
| **Population** | Older patients | Older adults | Adult patients | Patients with life limiting illness | Terminally ill patients | Older adults with life limiting illness | Adults | Adults | Older patients | Adults |
| **Setting** | Hospital | Hospital; community, Residential Aged Care | Hospital | Not stated | Not stated | Across care settings | Hospital; long-term residential care | Medical, surgical and trauma Intensive Care Units | Hospital | Hospital |
| **End of life/ Palliative care** | X | X | Not stated | ✓ | ✓ | ✓ | X | Not stated | Not stated | Unclear |
| **Evidence-base** | ✓ | ✓ | ✓ | X | X | ✓ | ✓ | ✓ | ✓ | ✓ |
| **Grading system** | SIGN and NICE | NHMRC | Oxford Classification | NA | NA | Categories of Evidence and Strength of Recommendations | GRADE | GRADE | Not stated | NHMRC |
| **Guiding principle/approach/goal** | Biomedical | Prevention of functional decline | Biomedical | Palliative care | Biomedical; Palliative care | Person centred; Whole person; Geriatric care principles; Palliative care | Person centred | Person centred; Biomedical; Relief of suffering; Improve clinical outcomes | Improve experience and outcomes for confused older people in hospital | Person centred; Quality and safety |

functional decline, improved clinical outcomes, relief of suffering, palliative, geriatric, whole person and/or patient centred approaches. Five different evidence-grading systems were used in the included guidelines' development. Two thirds of the guidelines provide the level of evidence underpinning recommendations (n=6). Only one expressly includes only recommendations supported by evidence (Barr et al., 2013). The Australian Commission of Safety and Quality in Health Care graded evidence within a separately published rapid review of the literature (Australian Commission on Safety and Quality in Health Care, 2013), which informed recommendations within the associated resources for managers, clinicians and consumers (Australian Commission on Quality and Safety of Healthcare, 2015b). Similarly, the National Institute for Health and Care Excellence full guideline contains detailed descriptions of evidence reviews and grading, although does not provide evidence grades for individual recommendations in the abbreviated document developed for clinicians (National Clinical Guideline Centre for Acute and Chronic Conditions, 2010). Four incorporate delirium care pathways (Australian Commission on Quality and Safety of Healthcare, 2015b; Australian Health Ministers' Advisory Council, 2010; NICE National Institute for Health and Care Excellence, 2015; NSW Agency for Clinical Innovation, 2014). The two most recent Australian guidelines more broadly encompassed recommendations pertaining to patients with *cognitive impairment* (i.e. dementia and delirium) (Australian Commission on Quality and Safety of Healthcare, 2015b; NSW Agency for Clinical Innovation, 2014).

*Delirium guidance for end-of-life and palliative care*

Most (n=7) of these delirium guidelines excluded or omitted reference to palliative care patients, evidence and/or explicit end-of-life care recommendations. In two of the remaining three guidelines, recommendations were not based on evidence. This finding is represented diagrammatically in Figure 4.1, and described in more detail below.

Three guidelines specifically address delirium care of palliative care patients (Canadian Coalition for Seniors' Mental Health, 2010; Department of Health and Human Services Tasmania, 2009; Palliative Care Expert Group, 2010). Of these, only the Canadian guidelines (Canadian Coalition for Seniors' Mental Health, 2010) provide levels of evidence for their recommendations. In contrast, both of the

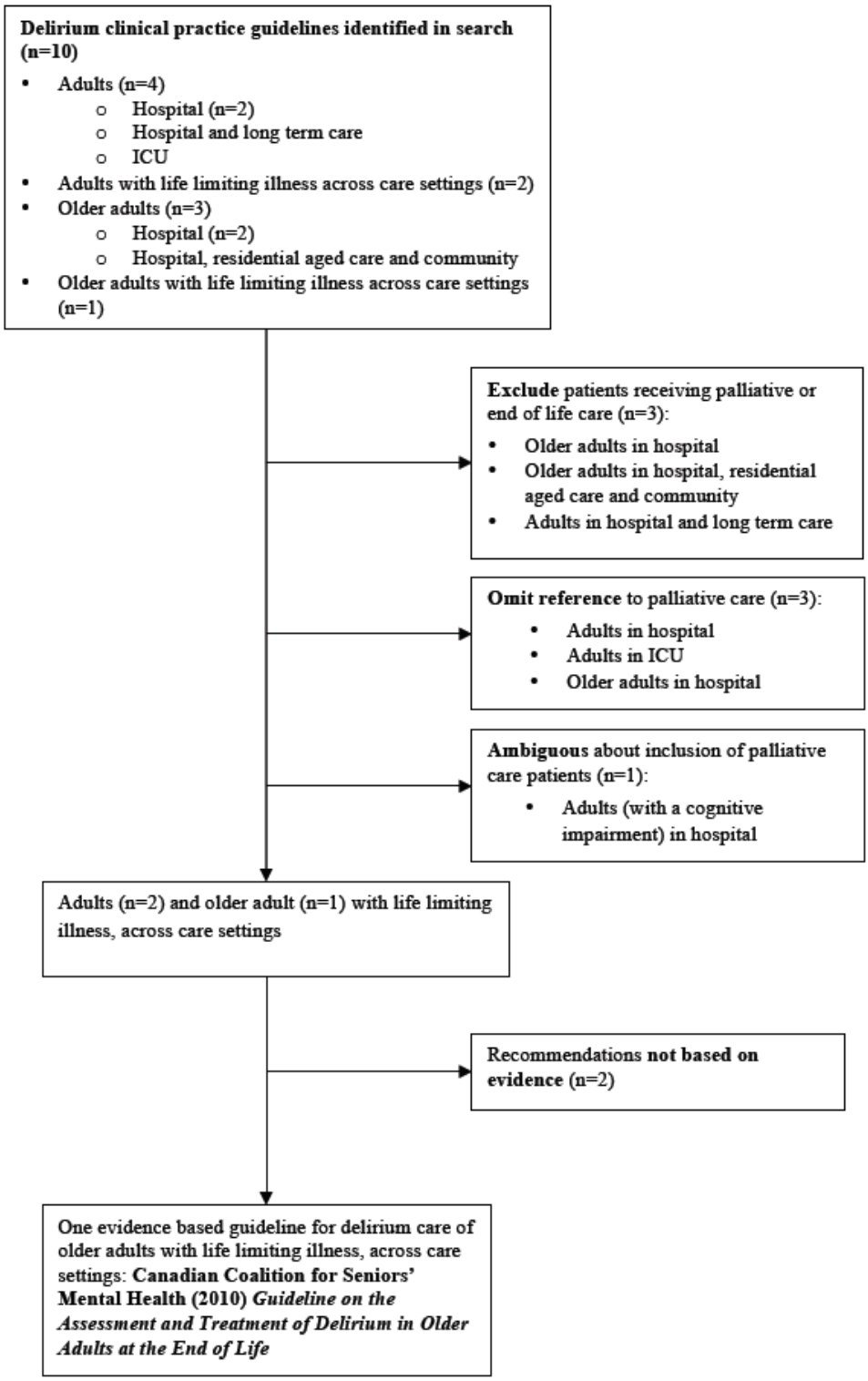


***Figure 4.1 Guidelines relevant to delirium in palliative care populations***

Australian guideline recommendations are based on consensus (Department of Health and Human Services Tasmania, 2009; Palliative Care Expert Group, 2010).

Palliative care populations were explicitly excluded from three guidelines for delirium care of older people (Clinical Epidemiology and Health Service Evaluation Unit Melbourne Health, 2006; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010; Royal College of Physicians and British Geriatrics Society, 2006). These guidelines either excluded evidence obtained from palliative care populations within their literature review and/or people receiving 'end-of-life' or palliative care from the scope of the guidance. Two guidelines, one focused on acute hospital populations and the other on older people in hospital, make no specific statements about optimal delirium care for palliative care patients (Michaud et al., 2007; NSW Agency for Clinical Innovation, 2014). While the ICU guidelines make no specific reference to patients who are expected to die in ICU nor use the term 'palliative care', their recommendations mirror a palliative approach to care, as they are focused upon reducing all ICU patients' suffering related to delirium (and pain and agitation) as well as longer-term negative sequelae (Barr et al., 2013). The two most recent Australian guidelines do not provide explicit recommendations pertaining to delirium and end-of-life care, even though the latter guideline stressed the importance of being alert to the potential for delirium to develop in people 'at risk of dying' (Australian Commission on Quality and Safety of Healthcare, 2015b; NSW Agency for Clinical Innovation, 2014).

Despite the limitations in scope and evidence related to palliative care populations, all recommendations for delirium recognition and assessment within the 10 included guidelines were examined and described in this environmental scan. This process provided insights into guideline similarities and differences, and enabled a consideration of their potential relevance for palliative care inpatients.

*Guideline recommendations*

*Awareness:* More than half of guidelines recommend clinicians' be aware of the risk of delirium (n=6) and assess patients' delirium risk on admission to the health care setting (n=7).

*Screening:* involves routine use of validated tools for delirium and/or cognition impairment on admission, and thereafter for high-risk patients and those whose

***Table 4.2*** *Guideline recommendations for delirium awareness, screening, confirmation and comprehensive assessment*

| Guideline | Prevention, diagnosis and management of delirium in older people in hospital (2006) | Management of Delirium in Older People (2006) | Delirium: Guidelines for general hospitals (2007) | Palliative Care Clinical Management Guidelines: Delirium (2009) | Therapeutic Guidelines Palliative Care (2010) | Assessment and Treatment of Delirium in Older Adults at the End of Life (2010) | Delirium: diagnosis, prevention and management (2010) | Management of Pain, Agitation, and Delirium in Adult Patients in the Intensive Care Unit (2013) | Key Principles for Care of Confused Hospitalised Older Persons (2014)* | Safe and high-quality care for patients with cognitive impairment (dementia and delirium) in hospital (2015b)* |
|---|---|---|---|---|---|---|---|---|---|---|
| **Awareness and risk assessment** | | | | | | | | | | |
| Clinician awareness of risk of delirium | ✓ | Expert opinion | | | | C | ✓ | | ✓ | ✓ |
| Assess risk of delirium on admission | | Expert opinion | ✓ | ✓ | | | ✓ | ✓ | ✓ | ✓ |
| **Screening** | | | | | | | | | | |
| Structured, routine, using validated tools | ✓ | Expert opinion | C | ✓ | | D | | B | ✓ | ✓ |
| Cognitive or delirium screening on admission | C | Expert opinion | C | | | D | ✓ | ✓ | ✓ | ✓ |
| Establish patients' baseline with family or others who know them well | C | Expert opinion | B | ✓ | | D | ✓ | | ✓ | ✓ |
| Serial cognitive assessment for high risk patients | B | C | C | | | D | | | | |
| Re-assess cognition if behaviour, cognition, clinical status or ADL deteriorates | | Expert opinion | | | ✓ | D | ✓ | | | ✓ |
| Trained, competent users of tools | | Expert opinion | C | | | C | ✓ | B | ✓ | ✓ |

| Guideline | Prevention, diagnosis and management of delirium in older people in hospital (2006) | Management of Delirium in Older People (2006) | Delirium: Guidelines for general hospitals (2007) | Palliative Care Clinical Management Guidelines: Delirium (2009) | Therapeutic Guidelines Palliative Care (2010) | Assessment and Treatment of Delirium in Older Adults at the End of Life (2010) | Delirium: diagnosis, prevention and management (2010) | Management of Pain, Agitation, and Delirium in Adult Patients in the Intensive Care Unit (2013) | Key Principles for Care of Confused Hospitalised Older Persons (2014)* | Safe and high-quality care for patients with cognitive impairment (dementia and delirium) in hospital (2015b)* |
|---|---|---|---|---|---|---|---|---|---|---|
| **Confirmation** | | | | | | | | | | |
| Tool | CAM or serial measures of cognition | CAM, CAM-ICU, DSI or DRS | CAM or CAM-ICU | CAM | | CAM, CAM-ICU or DSI | CAM or CAM-ICU | CAM-ICU or ICDSC | CAM | CAM, CAM-ICU, 4AT, SQiD |
| Diagnostic criteria | | DSM-IV | DSM-IV or ICD-10 | | | DSM-IV-TR | DSM-IV | | | |
| **Comprehensive assessment** | | | | | | | | | | |
| Investigate cause | C | Expert opinion | B | ✓ | ✓ | ✓ | ✓ | | ✓ | ✓ |
| Full history, physical examination and vital signs | C | ✓ | B | ✓ | | D | | | ✓ | ✓ |
| Routine investigations e.g. FBC, UEC, LFT, etc. | D | ✓ | B, C | ✓ | | D | | | ✓ | ✓ |
| Further investigations if indicated e.g. CT head, EEG. | C | ✓ | B, C | | | D | | | ✓ | |
| Need for referral if symptoms severe or persisting | ✓ | ✓ | ✓ | ✓ | | D | | | ✓ | ✓ |
| Interdisciplinary | ✓ | | | | | B | ✓ | B | ✓ | ✓ |
| Goals of care, patient's wishes and stage of illness | | | | ✓ | ✓ | D | | | | |
| Burden/likely effectiveness of intervention | | | | ✓ | | D | | | | |

| Guideline | Prevention, diagnosis and management of delirium in older people in hospital (2006) | Management of Delirium in Older People (2006) | Delirium: Guidelines for general hospitals (2007) | Palliative Care Clinical Management Guidelines: Delirium (2009) | Therapeutic Guidelines Palliative Care (2010) | Assessment and Treatment of Delirium in Older Adults at the End of Life (2010) | Delirium: diagnosis, prevention and management (2010) | Management of Pain, Agitation, and Delirium in Adult Patients in the Intensive Care Unit (2013) | Key Principles for Care of Confused Hospitalised Older Persons (2014)* | Safe and high-quality care for patients with cognitive impairment (dementia and delirium) in hospital (2015b)* |
|---|---|---|---|---|---|---|---|---|---|---|
| Review physical environment | | | | ✓ | | D | | | | ✓ |
| Decision-making capacity | | | | | | C | ✓ | | | ✓ |
| Safety | | | | | | D | ✓ | | | ✓ |
| Patient and family needs/level of distress/QOL | | | | ✓ | | D | ✓ | | ✓ | ✓ |
| Risk of falls and/or pressure areas | | | | | | C, D | | | ✓ | ✓ |
| Social/psychological OR spiritual OR cultural impact/needs | | | | | | D | ✓ | | ✓ | ✓ |
| Involve family in comprehensive assessment | | | | ✓ | | C | | | ✓ | ✓ |
| Assessment results in an individualised, documented and communicated plan of care | | | | | | D | | | ✓ | ✓ |

Code: **ADL** Activities of Daily Living **FBC** Full Blood Count **UEC** Urea Electrolytes and Creatinine **LFT** Liver Function Test **CT** Computed Tomography **EEG** Electroencephalogram **QOL** Quality of Life * Published after key informant interviews **NB:** There were numerous different evidence-grading systems used across the guidelines. Grades provided reflect grading assigned within the relevant guideline. A 'tick', rather than a grade, signifies where a recommendation or statement was made without a corresponding level of evidence assigned.

behaviour, cognition, clinical status or function deteriorates. Most guidelines recommend that clinicians establish the patient's baseline with family or others who know the patient well (n=8), and be trained and proficient in use of tools (n=7) (refer Table 4.3).

*Confirmation:* of delirium was frequently recommended via tools administered by trained clinicians (medical and nursing) (n=8) more often than by applying diagnostic criteria (n=4).

*Comprehensive assessment*: is multifaceted, encompassing: determining the cause of the delirium (via history taking, physical examination and various investigations); risk of falls, pressure areas and injury to self or others; level of distress; decision-making capacity; and family needs. More than half of guidelines (n=6) recommend interdisciplinary assessment, and the need to refer patients to appropriate psychiatric or geriatric specialists or specialist services if delirium is severe and/or persisting (n=7). Guidelines published from 2010 onwards were more likely to recommend the patients' social, psychological, cultural or spiritual needs be assessed, that the family be involved in the assessment process, and that an individualised care plan that addresses the patient and families' needs be developed (Table 4.2).

*Additional recommendations* within palliative care delirium guidelines included: assess patient goals of care, wishes and stage of illness to inform decision-making about investigation and intervention.

The two Australian palliative care guidelines varied markedly in the number of recommendations regarding delirium awareness, screening, assessment or confirmation. While the Department of Health and Human Services Tasmania (2009) provides 13 recommendations, the Therapeutic Guidelines for Palliative Care makes three recommendations pertaining to: i) re-assess the patient's cognition if behaviour, cognition, clinical status or ADLs deteriorates; ii) investigate cause; and iii) determine the patient's goals of care, patient's wishes and stage of illness (2010). The Canadian Coalition for Seniors' Mental Health guidelines contained the most extensive palliative care recommendations, explicitly framing actions within a whole person approach underpinned by principles of geriatric care (2010).

The Australian Commission on Safety and Quality in Health Care (2015b) resource was an amalgam of previous guidelines, pathways and best practice documents for

***Table 4.3 Guideline recommended cognition and delirium tools***

| Guideline | Prevention, diagnosis and management of delirium in older people in hospital (2006) | Management of Delirium in Older People (2006) | Delirium: Guidelines for general hospitals (2007) | Palliative Care Clinical Management Guidelines: Delirium (2009) | Therapeutic Guidelines Palliative Care (2010) | Assessment and Treatment of Delirium in Older Adults at the End of Life (2010) | Delirium: diagnosis, prevention and management (2010) | Management of Pain, Agitation, and Delirium in Adult Patients in the Intensive Care Unit (2013) | Key Principles for Care of Confused Hospitalised Older Persons (2014)* | Safe and high-quality care for patients with cognitive impairment (dementia and delirium) in hospital (2015b)*# |
|---|---|---|---|---|---|---|---|---|---|---|
| **Cognition tools** | | | | | | | | | | |
| MMSE | ✓ | C | C | | | C | | | ✓ | |
| AMT | ✓ | C | | | | | | | ✓ | ✓ |
| BOMC | | | C | | | | | | | |
| RUDAS | | | | | | | | | ✓ | |
| SIS | | | | | | | | | ✓ | |
| SPMSQ | | | | | | | | | ✓ | |
| Modified KICA | | | | | | | | | ✓ | |
| **Delirium tools** | | | | | | | | | | |
| CAM | ✓ | B | C | ✓ | | C | Moderate - short version | | ✓ | ✓ |
| CAM-ICU | | B | C | | | D | Moderate- high | A | | ✓ |
| DSI | | C | | | | D | | | | |
| DRS-98-R | | D | C | | | D | | | ✓ | |
| MDAS | | | C | | | D | | | | |
| CTD | | | | | | C | | | | |
| ICDSC | | | | | | | | A | | |
| 4AT | | | | | | | | | | ✓ |
| SQiD | | | | | | | | | | ✓ |

Code: **AMT**: Abbreviated Mental Test **BOMC**: Blessed Orientation Memory Concentration **CAM** Confusion Assessment Method **CAM-ICU** Confusion Assessment Method for the Intensive Care Unit **CTD** Cognitive Test for Delirium **DRS** Delirium Rating Scale **DSI**: Delirium Symptom Interview **4AT** Assessment test for delirium & cognitive impairment **ICDSC**: Intensive Care Delirium Screening Checklist **MDAS**: Memorial Delirium Assessment Scale **MMSE**: Mini-Mental State Examination **Modified KICA Modified** Kimberley Indigenous Cognitive Assessment **SIS** Six Item Screener **SPMSQ** Short Portable Mental Status Questionnaire **SQiD** Single Question in Delirium * Published after key informant interviews **#** Does not recommend a specific tool, but provides examples of brief, validated tools. **NB:** There were numerous different evidence-grading systems used across the guidelines. Grades provided reflect grading assigned within the relevant guideline. A 'tick', rather than a grade, signifies where a recommendation or statement was made without a corresponding level of evidence assigned.

care of patients with cognitive impairment, and subsequently includes the broadest range of recommendations. However, these recent Australian guidelines did not include assessment the patient's goals of care, wishes, stage of illness or burden of investigation and intervention for delirium (Australian Commission on Quality and Safety of Healthcare, 2015b)

### 4.5.7 Tools designed to screen, assess and/or confirm delirium and cognition impairment

A key omission within the Therapeutic Guidelines for Palliative Care (Palliative Care Expert Group, 2010) was the use of delirium or cognition tool(s), as all other guidelines stipulated the use of screening, assessment and/or confirmation tools to optimise identification of delirium (n=9) and/or cognitive impairment (n=7). Multiple delirium tools and cognitive assessment tools were recommended across the guidelines (n=16) (Table 4.3 and Appendix 1.3). The CAM (Inouye et al., 1990) was the most frequently recommended tool for either delirium screening or confirmation, followed by the Confusion Assessment Method for the Intensive Care Unit (CAM-ICU) for critical care settings (Ely et al., 2001). With the exception of these two tools and the Intensive Care Delirium Screening Checklist (ICDSC) (Bergeron, Dubois, Dumont, Dial, & Skrobic, 2001), there was only moderate-low levels of evidence of the validity and feasibility of these tools for the settings in which they were recommended. The most recent Australian guideline does not recommend a specific tool; instead stating brief validated tools should be used, and that clinicians understand the strengths and limitations of the tools used within their organisation and how to interpret the results (Australian Commission on Quality and Safety of Healthcare, 2015b).

The features of many of the delirium and cognition tools identified in this environmental scan are provided in Appendix 1.3.

### 4.5.8 Patient and family delirium information resources

Five patient and/or family delirium information resources were identified, four of which were developed in conjunction with included guidelines. Two resources are brochures (Australian Health Ministers' Advisory Council, 2010; Care of the Confused Hospitalised Older Persons Study, 2010), two are fact sheets (Department of Health and Human Services Tasmania, 2009; National Institute for Health and

Care Excellence, 2010) and one a booklet (Australian Commission on Safety and Quality in Health Care, 2014). While the National Institute for Health and Care Excellence fact sheet is specifically targeted at patients with delirium, it is incongruous that it is eight pages long (2010). No patient or family delirium decision aids were identified in the search. However, the Australian Commission on Safety and Quality in Health Care resource is presented as suggested actions that patients with cognitive impairment and their families can take to promote the quality and safety of their care while in hospital, and this resource is freely available online (2014).

### 4.5.9 Part C: Integration of delirium knowledge tools within palliative care inpatient unit systems

Correspondence between the systems of the three palliative care units and the identified delirium knowledge tools was minimal to non-existent (Table 4.4). Participant awareness of palliative care patients' risk of delirium was present and had resulted in research and quality improvement activity, yet despite this awareness and availability of validated tools for delirium screening or assess cognition, there were no systematic processes consistently applied to identify patients most at risk or who might be experiencing delirium at any of the three participating units. Patient and family information resources were not used, contrary to the philosophy of patients and families being partners in their own care and having their information needs met (Australian Commission on Safety and Quality in Health Care, 2011). Even where there was some use of validated tools, connection, coordination and collaboration between the different disciplines within the team were absent.

***Table 4.4 Mapping the integration of delirium knowledge tools within the systems of three palliative care inpatient units***

| Item | Practice | Degree of integration | Recommendation/resource |
|---|---|---|---|
| Awareness and assessment of risk of delirium | • Awareness of delirium as a problem for palliative care patients<br>• No delirium risk assessment undertaken | ≈ | • Clinicians to be aware of the risk of delirium<br>• Assess patients' delirium risk on admission to the health care setting |
| Screening for delirium or cognitive impairment | • Unstructured, non-specific or sporadic assessment of patients' delirium status on admission<br>• Sporadic or non-existent use of tools during admission, despite availability (n=5)<br>• Training in use of some tools, separately for different disciplines | ≈ | • Routinely at and during admission<br>• Structured, use brief, low-burden validated tools (variously recommended: n= 16)<br>Clinician training in use of validated tools<br>• Confirm with family or others who know the patient |
| Diagnosis and/or confirmation | • Validated tools for delirium diagnosis or confirmation not used<br>• No readily accessible information about the diagnostic criteria for delirium | ≠ | Use delirium diagnostic criteria or validated tools |
| Comprehensive assessment | • No point-of-care guidance for comprehensive assessment | ≠ | • Multifaceted: history, physical, social, psychological, cultural, spiritual, illness phase, goals of care, patient wishes, level of patient and family distress, safety, assessment results in a plan of care |
| Team approach | • Multidisciplinary<br>Specialist referral for psychiatric conditions other than delirium | ≠ | • Interdisciplinary<br>Specialist referral as required |
| Patient and family resources | None used | ≠ | • Two brochures, two fact sheets, one information booklet * |

Code: ≈ partial integration ≠ no integration * Developed after key informant interview

## 4.6 Discussion

Given the exclusion or omission of palliative care inpatients from the wider hospital population within the included guidelines, it is not surprising that there is minimal integration of delirium knowledge tools within the systems of the three participating Australian palliative care units. These palliative care units contrast with other inpatient speciality settings such as geriatric and intensive care units, where concerted efforts through a range of multifaceted interventions are successfully narrowing known delirium evidence-practice gaps (Godfrey et al., 2013; Pandharipande, Banerjee, McGrane, & Ely, 2010). The lessons learnt from these model endeavours will be helpful to the delirium reforms that are required in inpatient palliative care settings.

*Delirium guidance and hospital standards for palliative care populations*

Only two of the clinical guidelines were developed specifically for the Australian palliative care inpatient setting and neither is evidence-based (Department of Health and Human Services Tasmania, 2009; Palliative Care Expert Group, 2010). Delirium guidelines developed for older, critically ill and wider hospital populations puzzlingly exclude palliative care knowledge and/or make no explicit recommendations for delirious patients who are nearing the end of life. It is of concern that two current Australian delirium guidelines for palliative care patients do not provide evidence for their recommendations (Department of Health and Human Services Tasmania, 2009; Palliative Care Expert Group, 2010). Furthermore, the Therapeutic Guidelines for Palliative Care (2010) are widely promoted within healthcare and higher education (NSW eHealth) yet contain the least guidance for delirium recognition and assessment of all the 10 guidelines identified in this environmental scan.

Given the policy direction to promote a population based approach to palliative care (Palliative Care Australia, 2005), an equally important priority is that palliative care knowledge be more explicitly incorporated into delirium guidance, standards and policy for whole hospital populations. Delirium is significantly associated with increased mortality in the wider hospital (National Clinical Guideline Centre for Acute and Chronic Conditions, 2010), critical care (Salluh et al., 2015) and palliative care populations (Lawlor et al., 2000), while many patients in hospital settings have unmet palliative care needs (Virdun, Luckett, Davidson, & Phillips, 2015). Absence

of guidance for delirium care at the end of life is a lost opportunity to enhance end-of-life care across all hospital settings.

While guidelines are important resources, they are not of themselves sufficient to ensure practice change (Grol & Grimshaw, 2003). These palliative care units were clearly reliant upon and operated according to higher-level organisational direction, as participants revealed they had previously adapted their systems and practice according to policy direction and hospital governance for related aspects of care, such as falls prevention. Other systematic approaches to symptom screening, patient observation and team communication, such as Palliative Care Outcomes Collaborative (2014), 'Between the Flags' (Clinical Excellence Commission, 2015a) and ISBAR (Clinical Excellence Commission, 2015b) had proved feasible in this setting.

The recent release of the Australian Commission on Quality and Safety of Healthcare (2015b) resources represents a positive move in the Australian health care system towards strategies for patients with dementia and delirium across whole hospital populations, including for patients who are at risk of dying. The resources are linked to a proposed delirium clinical care standard, which includes indicators for delirium screening, assessment, prevention, identification and treatment of causes, prevention of falls and pressure injuries, reducing the use of antipsychotic medication and improving transition of patients from hospital care (Australian Commission on Quality and Safety of Healthcare, 2015a). This standard also proposes that the rate of delirium occurrence be measured: not as a key performance indicator, but to determine how often delirium is identified. The promise of this national initiative lies in its 'top-down' influence upon system change, as the meeting of standards through quality improvement is the basis upon which hospital accreditation is obtained. Unfortunately, the draft standard currently proposes that patients with *"…terminal delirium (delirium in patients receiving palliative care)…"* be excluded from these indicators, stating that these patients have *"…specific treatment needs…"* (Australian Commission on Quality and Safety of Healthcare, 2015a). Yet there is no evidence that palliative care patients require alternative approaches to delirium care. Treating delirium differently in palliative care patients per se, rather than according to the person's assessed circumstances and needs, perpetuates unfounded views that active approaches to delirium prevention, reversal and management are

less critical or possible for people receiving palliative care in either the specialist setting or elsewhere in the hospital (Lawlor et al., 2014). Ensuring quality and safety of care for all patients with delirium, wherever they are cared for within the hospital setting and whatever the stage of their illness, requires that this new clinical care standard consider palliative care patients included within the whole hospital population (To, Greene, Agar, & Currow, 2011).

*Promoting an interdisciplinary approach to delirium care*

Palliative care clinicians and managers during the key stakeholder conversations reported a *multidisciplinary* approach to delirium care. Whereby, each discipline appears to address delirium recognition and cognitive testing for patients separately, focused upon their individual disciplinary tasks, roles and learning needs. The current palliative care team approach is in contrast to the majority of guidelines that recommend interdisciplinary approaches to delirium education, practice and organisational systems (Table 4.2). An interdisciplinary approach purposely fashions coordinated and coherent connections between the different health care disciplines within a team to generate common methods, knowledge and perspectives in patient care (Newhouse & Spring, 2010). Interactions are centred around the needs of the patient and their family, who are actively involved in discussions and decision-making (Jessup, 2007; Newhouse & Spring, 2010). Interdisciplinary approaches are recommended as they have been demonstrated to be effective in improving knowledge, team behaviours and patient outcomes related to delirium (Hshieh et al., 2015; Sockalingam et al., 2014). Moving from a multidisciplinary team structure to an interdisciplinary structure would do much to dismantle the siloed delirium practices and learning of disciplines working within palliative care unit teams and re-connect them into an integrated whole for the benefit of patients.

Both senior nurses and physicians expressed concern about nurses' lack of knowledge about delirium and deficits in their assessment of patients experiencing agitation. It is apparent that palliative care nurses have minimal active involvement or clearly assigned roles in terms of delirium recognition and assessment within the existing multidisciplinary team structures. This gap highlights the enormous potential to improve the delirium care of palliative care patients through better defining the relevant role of nurses within the palliative care team and building their knowledge and skills.

In the close environs of palliative care inpatient units, it is feasible that interdisciplinary delirium conversations occur at least once daily and wherever possible at the bedside, rather than weekly multidisciplinary team meetings held away from the patient and family. Reserving team discussion to weekly meeting is at odds with the fluctuating nature of delirium and patient needs for an immediate team response. A patient and family focus is also key characteristic of interdisciplinary care (Nancarrow et al., 2013), yet readily available patient/family delirium resources were not used. There was also no evidence of other strategies to support patients/families informed participation in the delirium assessment and care processes.

*Delirium and cognition assessment tools*

Despite the availability of delirium and cognition tools, none were routinely used in these palliative care inpatient settings, even when they were included in one unit's admission documentation. The reasons for this gap were not fully explained by participants, but may be because the selected tools were not feasible for some palliative care inpatients. Determining the most appropriate and inclusive tools for this setting is challenging given the multitude that have been developed, tested and recommended over time (Adamis, Sharma, Whelan, & MacDonald, 2010), and requires a 'sifting through' process of consideration.

Brief and observational tools are required as many palliative care patients will be fatigued, breathless, delirious, and/or unable to communicate verbally. Of the recommended tools, the briefest are the: 4AT (McLullich, 2014), Nu-DESC (Gaudreau et al., 2005), Single Question in Delirium (SQiD) (Sands, Dantoc, Hartshorn, Ryan, & Lujic, 2010), and CAM-ICU (Ely et al., 2001). Each of these delirium tools has fewer than five items and takes less than two minutes to complete. These tools can also be used with drowsy and/or non-verbal patients and administered by nurses, with minimal training (Appendix 1.3). While the Nu-DESC and the SQiD have been validated in oncology inpatient populations (Gaudreau et al., 2005; Sands et al., 2010), none have been so within palliative care. Only two of the tools identified in this environmental scan were validated in palliative care: the CAM, for junior physicians (Ryan et al., 2009); and the MDAS (Breitbart et al., 1997). However, the CAM performs poorly if given to clinicians to use without sufficient training (Lemiengre et al., 2006), and there is no data reporting the

performance over time of either of these tools. Moreover, both the CAM and the MDAS take around 10 minutes to complete, making them more suited for research purposes rather than routine clinical use.

Although delirium tools are not yet sufficiently tested or implemented in palliative care settings (Hosie, Davidson, Agar, Sanderson, & Phillips, 2013; Ryan et al., 2009), there is emerging evidence that their use by nurses in palliative care inpatient settings is effective and feasible. Rao et al (2011) reported that palliative care nurses successfully integrated screening into their daily practice using an observational and shortened version of the CAM (Inouye, 2003), while Gagnon et al (2012) reported the successful implementation of the CRS (Williams, 1991) by bedside nurses in seven palliative care units/hospices during a three-year delirium prevention trial (Gagnon et al., 2012). Of note is that a full CAM was applied in only 39% of participants in the later study, due to patients' impaired consciousness or perceived burden of the structured interview, which flags the limitations of using the full CAM version in palliative care settings (Gagnon et al., 2012). The CAM has since been developed into two briefer tools: the five minute short-CAM and three minute 3D-CAM (Marcantonio et al., 2014); as well as a family informant version, the FAM-CAM (Hospital Elder Life Program, 2015), which hold promise within the palliative care setting. Recently, Detroyer et al (2014) tested the Delirium Observational Screening Scale (DOSS) (Schuurmans, Shortridge-Baggett, & Duursma, 2003) in a palliative care unit, reporting good diagnostic validity and nurse perception that the tool was user-friendly. However, as the DOSS relies on patients being able to communicate verbally its applicability is somewhat limited in this inpatient population (Detroyer et al., 2014). Another brief, observational and therefore potentially useful nurse-rated delirium screening tool is recently validated the 'Recognizing Acute Delirium As part of your Routine' (RADAR) (Voyer et al., 2015).

### 4.6.1 Strengths and limitations

The limitations of this environmental scan include that the snowball, rather than systematic, search strategy means potentially relevant delirium knowledge tools may have been omitted. However, the recursive nature of the snowball search over four years generated a large volume of data that revealed the availability and limitations of delirium knowledge tools for the palliative care inpatient setting. The quality of

the included delirium knowledge tools was not systematically appraised, but the level of evidence used to generate the recommendations was considered. The use of a structured questionnaire enabled a focused discussion within the group interviews, but it was not feasible to ask a group of participants to assign a numerical score to prioritise relevant delirium system supports. The decision to not digitally record the interviews and reliance on field notes may have resulted in omission of relevant data. Only three Australian palliative care inpatient services were included in this study, and all were in NSW and had delirium research studies being undertaken. While at one level the findings about minimal integration of delirium knowledge tools may be not representative of inpatient palliative care more widely within Australia, or internationally, these units were highly resourced, research active, metropolitan palliative care inpatient services that have the greatest potential opportunities to integrate the suite of delirium knowledge tools into usual care practices. These units are considered to be exemplars of palliative care practice and knowledge and in this capacity provide learning opportunities and supports to other specialist and primary palliative care teams. Given their exemplar status the onus is on these services to provide the best evidence-based delirium care. The lack of a definitive process for environmental scanning methodology means it is more difficult to ensure and report study rigour, and this is another limitation. Despite these limitations, the flexible and pragmatic methodology of an environmental scan has enabled the first descriptive analysis of the relationship between delirium knowledge tools and relevant systems of care within palliative care inpatient units.

### 4.6.2 Implications for practice and research

Addressing gaps in palliative care nurses' delirium knowledge, recognition and assessment practice is clearly required (Agar et al., 2012). To optimise the likelihood of improvement in patient outcomes, interventions to build nurses' delirium capabilities must be recognised as one component of broader, interdisciplinary interventions for delirium care (Brummel et al., 2013; Sockalingam et al., 2014). Delirium must become 'everyone's business' within the palliative care team. Each discipline needs to be aware of and capable of fulfilling their unique role. Each team member also need to understand the role of their colleagues, and how their roles might better fit together as a congruent whole to meet the delirium needs of the patient and their family. For nurses caring for patients during the night when

the symptoms of delirium are just as likely to occur, ensuring that their patient observations are documented, communicated and responded to appropriately must be factored into the 24-hour interdisciplinary team approach. Adopting an interdisciplinary approach to delirium care would enable not only a more holistic and patient centred approach to care, but also greater efficiencies through the streamlining of care processes (Jessup, 2007; Nancarrow et al., 2013).

Investigation of the psychometric properties of brief, observational tools in this setting is urgently required. The uptake of brief delirium screening tools is likely to be greater if there was more robust evidence to guide appropriate selection of tools for routine use within inpatient palliative care.

Despite minimal explicit reference to palliative care, recommendations for delirium recognition and assessment from guidelines developed for other patient populations could inform palliative care (Bush et al., 2014). An important step in knowledge translation is development of evidence-based delirium guidelines for the Australian palliative care inpatient setting, which will require a systematic adaptation process (Fervers et al., 2011) and ongoing research to build more rigorous evidence regarding delirium care for palliative care populations (Lawlor et al., 2014).

A potential powerful driver for change will be a mandatory delirium clinical care standard that holds potential to provide vital impetus and direction for palliative care inpatient services to make necessary improvements to their systems of delirium care (Australian Commission on Quality and Safety of Healthcare, 2015a). This signifies the need for the sector to advocate for the inclusion of palliative care patients in wider organisational initiatives for delirium within the hospital system, given the prevalence and incidence of delirium for patients receiving care in this specialist setting (Hosie et al., 2013).

## 4.7 Conclusion

Delirium knowledge is missing from the systems of three highly resourced Australian specialist palliative care inpatient units and consequently delirium recognition and assessment guidance was not readily available for the nurses of these units. While numerous delirium knowledge tools are available, these are almost completely disconnected from inpatient palliative care populations, evidence and practice.

The findings of this environmental scan highlight the urgent need for positive action to address the organisational barriers to delirium recognition and assessment by nurses working within palliative care inpatient units.

The following chapter reports a cross-sectional study of delirium point-prevalence in an Australian palliative care inpatient population, which was the beginning point of the local ‘action’ component of the DePAC project.

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# Chapter 5: Measuring delirium point-prevalence in two Australian palliative care inpatient units

## 5.1 Chapter preface

Chapter four mapped the extent of integration of delirium knowledge tools within three Australian palliative care inpatient units using an environmental scan method. The environmental scan found that while numerous delirium knowledge tools are available, they are not integrated into inpatient palliative care unit systems and so are not readily available to nurses working in this setting. This study also revealed that palliative care team members wanted confirmation of local delirium prevalence rates prior to making any changes to existing delirium recognition and assessment system and practices.

Chapter five reports Study three, which was a 'snap-shot' examination of the combined daily prevalence of delirium within the patient populations of two of these palliative care settings in Sydney, Australia. This study addresses the first research question of the DePAC project: '*What is the epidemiology of delirium in the palliative care inpatient population?*' The feasibility of a delirium screening, severity assessment and diagnosis process within the palliative care inpatient setting, using validated tools and DSM-5 diagnostic criteria for delirium, was also explored as part of Study five, reflecting the knowledge-to-action step of adapting knowledge tools to the local context.

## 5.2 Introduction

To advocate for delirium system and practice change within palliative care inpatient settings, confirmation of local delirium occurrence rates is needed (Bonita, Beaglehole, & Kjellstrom, 2006). Currently there is minimal delirium occurrence data for Australian palliative care patients. One Australian study (Rainsford, Rosenberg, & Bullen, 2014) recently reported delirium incidence of 43% within three days of admission to a palliative care unit, using the DRS-R-98 (Trzepacz, 2001) and the CAM (Inouye et al., 1990) as the measurement tools. The Australian researchers later reported practical and ethical challenges in recruiting palliative care patients into delirium research, with only 51 of 100 consecutive patients able or willing to participate in their study (Rainsford, Bullen, & Rosenberg, 2014). With the challenges of conducting ethical and rigorous delirium research in palliative care populations in mind (Sweet et al., 2014), a low burden process to ascertain the point-prevalence of delirium within one 24-hour period was devised and implemented within the DePAC project.

## 5.3 Aims

This study aimed to:

Ascertain the 24-hour point-prevalence of delirium in an Australian palliative care inpatient population; and

Test the feasibility and acceptability of the delirium measurement methodology.

## 5.4 Method

### 5.4.1 Design

A prospective, cross sectional study of delirium 24-hour point-prevalence within a palliative care inpatient population.

### 5.4.2 Setting and participants

The two palliative care units involved in the study are situated within sub-acute hospitals in Sydney, Australia. Each unit provides palliative care for patients with a life-limiting illness who require symptom management, respite and/or terminal care. Other characteristics of the sites are provided in Chapter three. Data were collected at Site 1, a 39-bed unit, over a 24-hour period during November 2013; and at Site 2, a 20-bed unit, over a 24-hour period during January 2014.

*Sample size*

The number of prospective consecutive patients within each unit during each 24-hour observation period determined the sample size.

### 5.4.3 Study measures and processes

*The th*ree-step process used to screen, assess and confirm delirium is described below, and provided diagrammatically in Figure 5.1.

*Step 1: Delirium screening*

Clinical nurses were asked to complete the Nu-DESC (Appendix 1.3) at 1400, 2200 and 0600 hours for all patients during the *a priori* observation days (Gaudreau, Gagnon, Harel, Tremblay, & Roy, 2005). Nurses were familiar with the Nu-DESC, as it had been available to them for a three-year period, during the course of a randomised controlled trial of pharmacological interventions for delirium (Agar, 2010). Over the three-year period nurses had received intermittent training (didactic and one-on-one teaching) on its application, consistent with the level of information provided during its original validation study (Gaudreau, 2013; Gaudreau et al., 2005). Nurses were also provided with information about the Nu-DESC prior to this present study. Patients were considered to have a positive delirium screen if they had a Nu-DESC score of $\geq$2 during any shift within the 24-hour observation period.

*Step 2: Delirium severity assessment*

For patients who scored $\geq$2 on the Nu-DESC and who were able and willing to participate, the trained researcher [AH] administered the MDAS (Breitbart et al., 1997) (Appendix 1.3). The MDAS was completed using a combined patient interview and preceding 24-hour information gathering approach, including reference to the Nu-DESC item scores assigned by nurses (Neufeld et al., 2014). The researcher was responsible for MDAS completion, as the Medical Directors of participating units indicated that physicians (particularly junior medical officers) were not able to commit the time required to undergo MDAS training nor administer the assessment with patients.

*Step 3: Delirium diagnosis*

At the end of the 24-hour observation period, the researcher met with the physician caring for those patients who scored $\geq$2 on the Nu-DESC. Physicians included

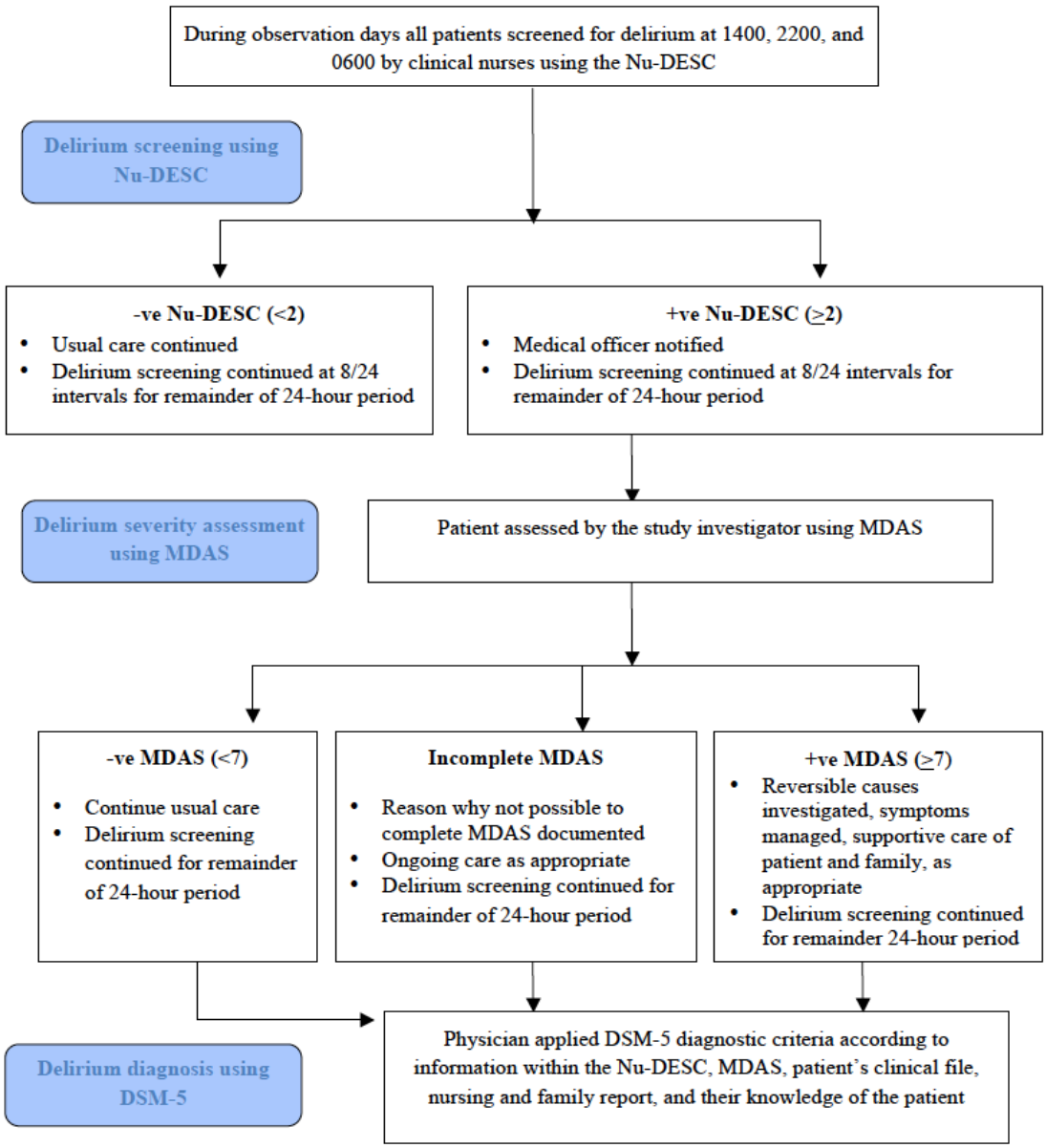


***Figure 5.1 Delirium screening, assessment and diagnostic process***

resident medical officers and staff specialists, who had each been provided with information about the study and the DSM-5 diagnostic criteria for delirium (Appendix 1.2) (American Psychiatric Association, 2013). The researcher provided the treating physician with information collected for each patient via the audit method (Appendix 3), as well as relevant information volunteered by the patient, family or nurse to the researcher. Physicians considered this information, along with their own assessment of the patient during the previous 24-hours, knowledge of their medical history, nursing observations communicated to them and information from

the clinical record. Using all available information, the physician determined if criterion A-E of the DSM-5 diagnostic criteria for delirium applied (Neufeld et al., 2014). If the researcher believed that the physician's determination of any of the criteria did not correspond with the patient's data, discrepancies were discussed until consensus was achieved. In instances where the physician did not have enough information to determine whether an individual criterion was met (for example, whether disturbances to attention represented a change from the patient's baseline), that criterion was not assigned and the patient was considered to not meet the DSM-5 diagnostic criteria for delirium.

Table 5.1 outlines additional measures of patient function and palliative care phase collected by the researcher during the observation period. These three patient measures are routinely undertaken by nursing staff at least once daily for all inpatients of the participating palliative care units, through the Palliative Care Outcomes Collaborative (PCOC) system of daily screening of patients' symptoms (2014a).

### 5.4.4 Inclusion and exclusion criteria

All patients admitted for at least one 8-hour shift during the 24-hour observation period were included for delirium screening using the Nu-DESC. All patients with a positive Nu-DESC were considered for a MDAS, but the MDAS was not administered if the patient was in the terminal phase, unable to speak and whenever their physician or nurse considered it otherwise not appropriate for the researcher to approach them. Assignment of the DSM-5 diagnostic criteria for delirium was undertaken for all patients who screened positive for delirium.

### 5.4.5 Consent and communication processes

Ethical approval for waiver of written patient or proxy consent was sought and obtained for this study. Study information posters (Appendix 5) were placed in the common areas of each unit for the duration of the study, with patients and families given the option of electing for non-participation in any aspect of the study. Prior to undertaking the MDAS, the investigator gave patients, and their family if present, scripted verbal information about the study and advised them that their participation in the MDAS assessment was voluntary. Verbal consent was obtained from patients before proceeding. The MDAS was not undertaken if the patient refused or if their

***Table 5.1 Functional and palliative care phase measures***

| 5.4.6 Tool | 5.4.7 Description |
|---|---|
| Australian-modified Karnofsky Performance Status (AKPS) | The AKPS is a validated measure of a patient's overall performance status, using 10-point increments along a scale of 100-10. A score of 100 denotes normal function with no evidence of disease, decreasing to a minimum score of 10, assigned when patients are comatose or barely rousable. Scores correlate with patient survival times (Abernethy, Shelby-James, Fazekas, Woods, & Currow, 2005). |
| Resource Utilisation Groups - Activities of Daily Living (RUG-ADL) | The RUG-ADL is a validated functional assessment tool, which assigns a score of 4-18, based on what a patient does, rather than they can do, in relation to bed mobility, transfers, eating and toileting. Higher scores indicate that the patient needs more assistance to undertake these activities and that more resources are required to provide this assistance (Fries et al., 1994). |
| Palliative Care Phase | The palliative care phase classification is not a validated tool, but is widely used within Australian palliative care services to describe the needs of the patient and their family, and prompt timely and appropriate responses by the palliative care team. Phases are:<br>1. Stable: problems and symptoms are adequately managed and there is a plan of care;<br>2. Unstable: urgent intervention required because a new symptom or problem develops, or an existing problem rapidly escalates;<br>3. Deteriorating: denotes a gradual decline in function AND worsening of an existing problem or development of a new but anticipated problem;<br>4. Terminal: death is likely within days;<br>5. Bereavement: post death support (Eagar, Green, & Gordon, 2004). |

family member refused on their behalf. Reasons for non-completion of the MDAS were recorded.

All researcher interactions with patients were documented in the clinical record. MDAS results were reported to the physician and nurse caring for the patient on the day of assessment.

### 5.4.8 Data collection

The researcher collected data pertaining to patient demographics, diagnosis, functional status, palliative care phase, Nu-DESC, MDAS and DSM-5 status during the observation period using a prospective audit method.

### 5.4.9 Data analysis

Data were entered into the Statistical Package for the Social Sciences (SPSS) V.21 (IBM Corp., 2012). Descriptive statistics were used to report patient demographics, phase, function and the proportion of patients who: i) screened positive for delirium i.e. a score of $\geq$2 on the Nu-DESC on any shift within each 24-hour period; and ii) who met the DSM-5 diagnosis of delirium. Rates of at least once daily and per shift completion of the Nu-DESC were reported as frequencies and percentages, as were completion rates of the MDAS and DSM-5 for patients with a positive Nu-DESC screen.

## 5.5 Results

### 5.5.1 Patient demographics

47 patients were screened for delirium (Site 1 = 28; Site 2 = 19). The mean age of the total sample was 74 years (SD ±10) (Table 5.2). The majority of patients were male (60%) and had a malignant primary diagnosis (96%). Five patients (11%) had a diagnosis of an existing chronic cognitive impairment documented at admission.

***Table 5.2 Patient demographics (n=47)***

| **Characteristic** | **Frequency (%) Mean (s.d.)** |
|---|---|
| Age in years, mean (±SD) | 74 (±10) |
| Number aged >65 | 39 (79%) |
| Male sex, n (%) | 28 (60%) |
| Aboriginal or Torres Strait Islander (ATSI) status | |
| Not ATSI | 37 (79%) |
| ATSI | 1 (2%) |
| Not documented | 9 (19%) |
| Country of birth, n (%) | |
| Australia | 15 (32%) |
| Elsewhere | 21 (45%) |
| Not documented | 11 (23%) |
| Primary language, n (%) | |
| English | 35 (75%) |
| Other than English | 10 (21%) |
| Not documented | 2 (4%) |
| Primary diagnosis | |
| Malignant | 45 (96%) |
| Non-malignant | 2 (4%) |
| Diagnosis of an existing chronic cognitive impairment | |
| Yes | 5 (11%) |
| Length of stay in days, median (IQR) | 14 (14) |

### 5.5.2 Patient function and palliative care phase

Frequencies for palliative care phase and function measures (RUG-ADL and AKPS) are provided in Figure 5.2. Patients' functional abilities varied widely, and nurses considered that most patients' palliative care phase classification were either 'stable' or 'deteriorating' (n = 40; 85%). Only two of the 47 patients were considered by palliative care nurses to be in the 'terminal phase' (i.e. the last days of their life) (Eagar et al., 2004).

### 5.5.3 Patient inclusion and completion of study measures

*Step 1: Delirium screening rates*

No patient or family member requested an opt-out of delirium screening. All patients admitted for more than eight hours (one nursing shift) on each observation day were screened for delirium at least once in 24-hours (100%). Nearly all of the eight hourly Nu-DESC scores were completed (97%).

*Step 2: Delirium severity assessment rates*

Of 16 patients who screened positive for delirium (Nu-DESC $\geq$2), the MDAS was not attempted for 12, for several reasons: six patients were unable to complete the MDAS because they were drowsy, unable to speak or incoherent, and/or dying; two were non-English speaking; three had left the unit short-term (e.g. for medical appointments or to visit their home); one was discharged; and one refused. Of the four MDAS that were undertaken, two were not fully completed, due to one patient's refusal to answer the short-term memory question (Item 3) and another's fatigue. This resulted in a MDAS completion rate of only 12.5% (n=2/16). Because of the low overall completion rate, MDAS data were not subjected to further analysis. Patients who were not able to complete the MDAS were not withdrawn from the study, as physicians' assignment of the DSM-5 diagnostic criteria were informed by multiple sources of information.

Family members (n=3) who were present with patients, and observed their loved one's difficulties responding to the MDAS questions, cried, appeared distressed and/or urged patients to respond and answer correctly. Family members afterwards volunteered the researcher information about who the patient was as a

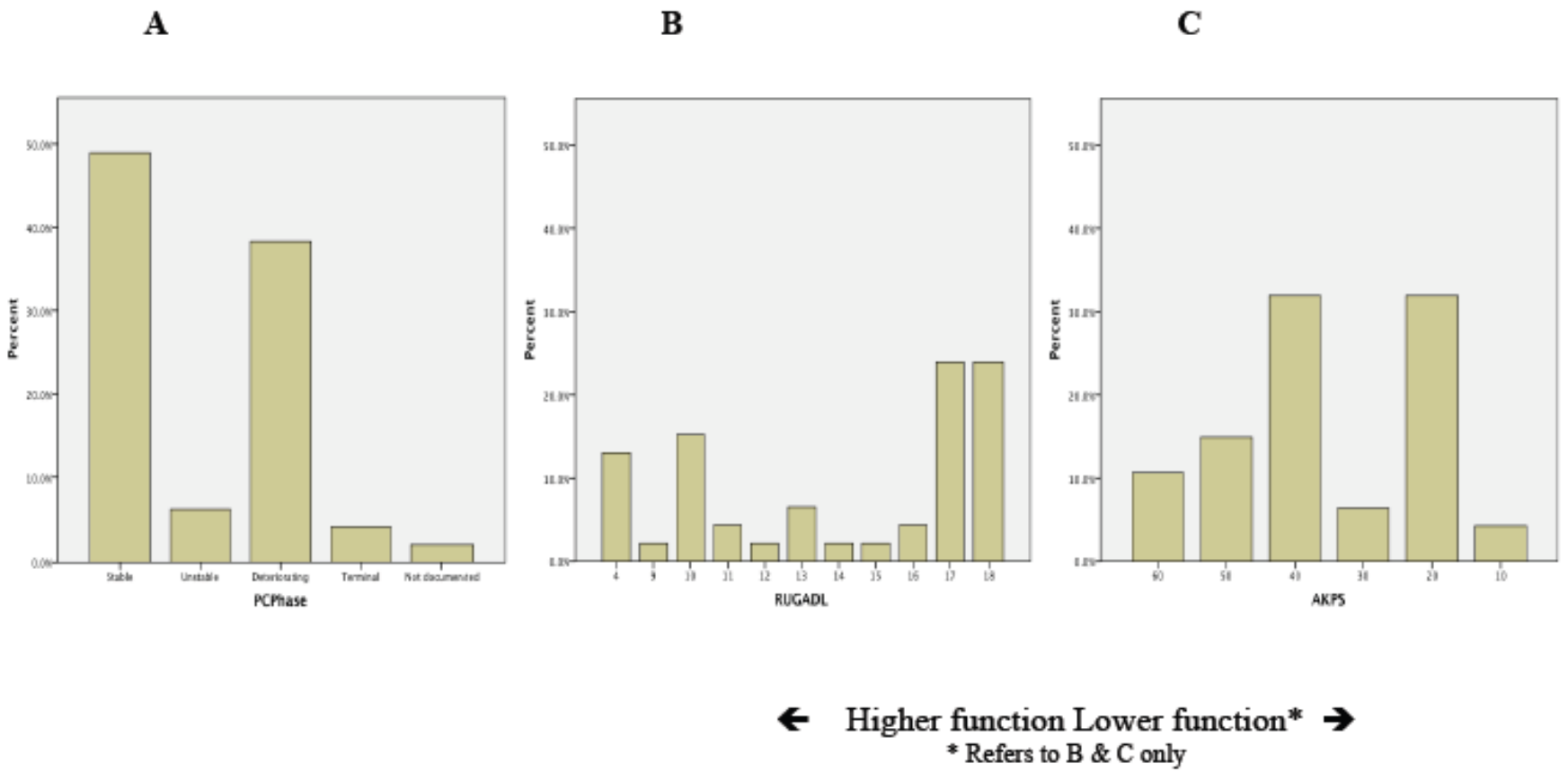


***Figure 5.2 Frequencies of palliative care phase and function measures (RUG-ADL and AKPS)***

person, speaking of their previous cognitive abilities, occupation, achievements, interests, and when the cognitive and attention changes had first occurred. The three family members also offered their insights into what they believed had contributed to the patient's recent deterioration in attention and cognition.

*Step 3: Delirium diagnosis completion rate*

Physicians applied the DSM-5 diagnostic criteria for all 16 patients who screened positive using the Nu-DESC, which was a 100% completion rate. Completion rates of delirium measures (Nu-DESC, MDAS, and DSM-5 diagnostic criteria) are tabulated below (Table 5.3).

***Table 5.3 Completion rates of delirium measures***

| Measure | Completion rate |
|---|---|
| Nu-DESC: at least once daily | 47/47 (100%) |
| Nu-DESC: 8-hourly | 136/140 (97%) |
| MDAS | 2/16 (12.5%) |
| DSM-5 diagnostic criteria | 16/16 (100%) |

### 5.5.4 Proportion of patients with a positive Nu-DESC and diagnosed as delirious

Of the 47 patients screened, 34% (n=16) had a positive Nu-DESC for at least one eight-hour shift during the 24-hour observation period. Amost one in five (19%; n=9) of patients met the DSM-5 delirium criteria (Figure 5.3).

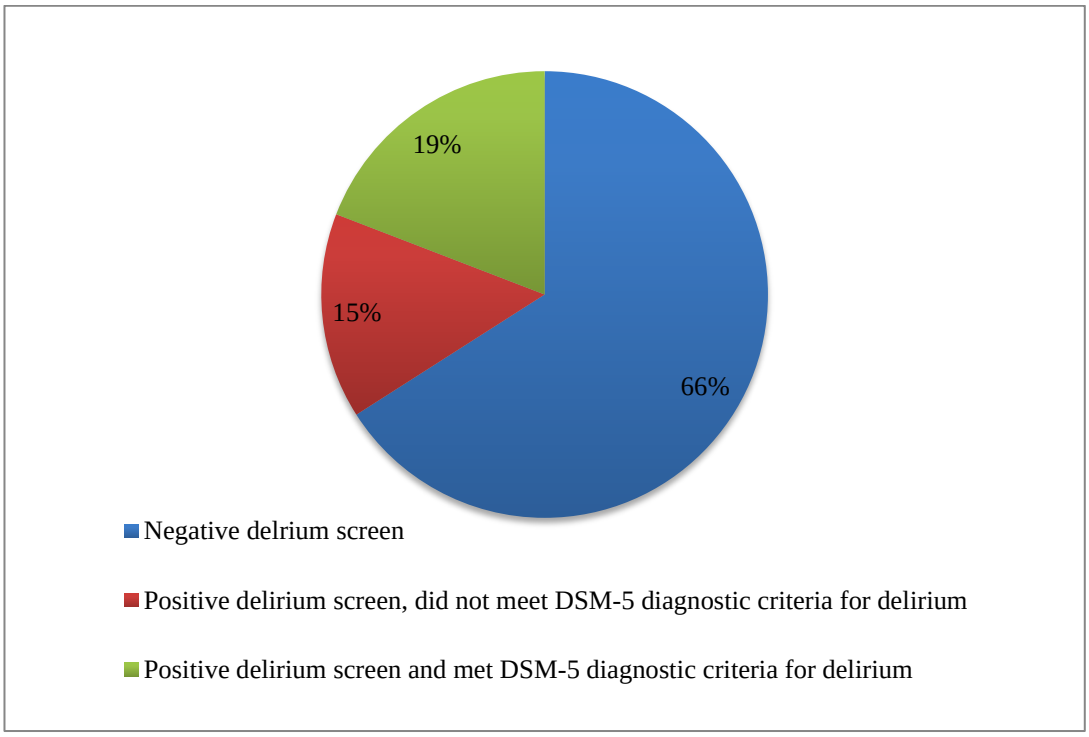


***Figure 5.3 Proportion of patients with a positive Nu-DESC and diagnosed as delirious***

## 5.6 Discussion

While only a small pilot study, there were a number of valuable observations related to delirium prevalence, age of the population, and the feasibility and acceptability of the delirium measurement methodology.

### 5.6.1 Delirium point-prevalence

Over one third of patients in our study had a positive Nu-DESC at least once in the 24-hour period. Within 8-24 hours of a positive delirium screen, over half of these patients (n=9) were determined by their treating physician to meet the DSM-5 diagnostic criteria for delirium. The study process resulted in a 24-hour delirium point-prevalence of 19% in this Australian inpatient palliative care population.

This 24-hour delirium point-prevalence of almost one in five palliative care patients is not surprising, although slightly lower than reported previously. The systematic review reported in Chapter two highlighted wide ranging prevalence (Hosie, Davidson, Agar, Sanderson, & Phillips, 2013), although only one included study measured delirium point-prevalence (Spiller & Keen, 2006). Using the CAM and DSM-IV diagnostic criteria for delirium, 29.4% of 126 patients of eight Scottish specialist palliative care units were found to be delirious in a 48-hour period (Spiller & Keen, 2006). More recently, Ryan and colleagues (2012) reported a 24-hour delirium point-prevalence of 20% across a whole hospital population, using the CAM, DRS-R-98 and DSM-IV (2013). It is possible that the lower proportion of palliative care patients found to be delirious in this DePAC project study relates to the small sample size. There were also challenges in accurately establishing if the observed changes in patients had recently occurred, because their cognitive function and delirium history and status were not routinely documented on admission. Moreover, the DSM-5 criteria is potentially less inclusive than the DSM-IV (Meagher et al., 2014).

### 5.6.2 The population

Characteristics of this patient population are worthy of note. Firstly, these patients had a broad range of functional ability and according to the palliative care phases assigned by the nurses caring for them, most patients were not in the last days of life. While these functional and phase assessments are subjective and prone to inconsistent reporting, they are a daily reporting requirement for Australian palliative care services with data reliability supported by continued quality improvement (Palliative Care Outcomes Collaborative, 2014b). Nevertheless, if correct, they indicate that most of these palliative care patients were not imminently dying, again warranting that active delirium recognition, assessment and intervention be routinely instigated for this inpatient population (Australian Commission on Quality and Safety of Healthcare, 2015a). Careful discernment of a patient's whole situation and needs is the vital step to ensuring that a reversible delirium is not assumed to be an inevitable result of advanced illness, or that dying patients are not subjected to inappropriate assessment and futile investigation (Lawlor et al., 2014). This individualised approach to delirium care is essential for all patients receiving end of

life care, in any hospital setting (Australian Commission on Quality and Safety of Healthcare, 2015b).

These patients were a geriatric oncology population, meaning they were predisposed to delirium not only because of their advanced disease, but also by their older age (National Clinical Guideline Centre for Acute and Chronic Conditions, 2010; Uchida et al., 2015). Optimal inpatient care of older people includes routine cognitive and delirium assessment, preventative and management strategies for cognitive impairment, and cautious, evidence-based use of pharmacological interventions for symptom management (Australian Commission on Safety and Quality in Health Care, 2014; Soo, 2013). For example, benzodiazepines are commonly prescribed to palliate breathlessness and other symptoms, such as insomnia, anxiety and even delirium itself (Clark & Currow, 2015), despite inconclusive evidence of their effectiveness and recommendations that this class of medication be avoided in people at risk of delirium (Australian Commission on Safety and Quality in Health Care, 2013; Clegg & Young, 2011). By definition, this includes older patients receiving palliative care, for whom non-pharmacological interventions for the relief of breathlessness are effective and safer than benzodiazepines (Bausewein, Booth, Gysels, & Higginson, 2008).

The low proportion (11%) of patients in this study reported as having a diagnosis of an existing chronic cognitive impairment may possibly under-represent the true occurrence, which is estimated to be at least 20-25% of people aged over 70 years who are admitted to hospital (Australian Commission on Safety and Quality in Health Care, 2013). A diagnosis of cancer increases the risk of longer-term cognitive impairment, while dementia and mild cognitive impairment are under-recognised and under-diagnosed in hospitalised patients (Australian Commission on Safety and Quality in Health Care, 2013; Heflin et al., 2005). As the environmental scan noted, patients' cognition is not routinely assessed on admission at either of the participating units. Therefore it is quite possible that some patients had a pre-existing cognitive impairment that was not identified and/or documented in their clinical record. This gap points to the importance of routine assessment and documentation of patients' baseline mental function upon admission to a palliative care unit, because this information is essential in order to establish if, when and to what degree change has occurred.

### 5.6.3 Feasibility and acceptability of the delirium measurement process

Studies measuring delirium occurrence commonly report challenges in recruiting palliative care patients, who are often very unwell and have difficulty communicating (Fang et al., 2008; Rainsford, Bullen, et al., 2014). Family and clinician gatekeeping reflect their valid concerns that vulnerable patients not be unduly burdened by research and clinical assessments. Burden of study consent and assessment processes for patients and family must therefore always be anticipated, carefully weighed and addressed in the designing and conduct of delirium research within this patient population (Sweet et al., 2014). The use of the low burden Nu-DESC in this study supported ethical waiver of consent to screen patients for delirium and inclusion of all admitted patients. The observational Nu-DESC was also inclusive of patients whose primary language is other than English, as was the case for one in five of this patient population.

Nurses' use of the Nu-DESC was supported through prior in-service training, study information posters, positioning of the tool amongst patients' bedside charts and support on the day, such as verbal reminders and information as requested. Even so, the optimal Nu-DESC completion rate was surprising. This short trial period confirms confidence in the potential for the Nu-DESC to be a readily applied tool by nurses for the whole population within palliative care inpatient settings, once tested in this setting and if accompanied by implementation strategies at the local level (Brummel et al., 2013).

The MDAS proved not feasible or acceptable for most patients. Those patients who screened positive for delirium were almost all considered by their physician and/or nurse to be unable to participate in a structured interview for research purposes. The remaining four patients who did participate struggled to answer the MDAS questions. MDAS items can be prorated but, as the researcher had no prior clinical contact with patients, this approach was not adopted to minimise measurement bias (Lawlor et al., 2000). The MDAS is well validated (Breitbart et al., 1997; Lawlor et al., 2000), aids in confirming cognitive, attention and psychomotor disturbances and whether patients met the DSM-5 delirium diagnostic criteria A and C (Appendices 1.2 and 1.3), yet it appears to not be a feasible delirium severity tool overall for this palliative care population even had clinicians, rather than the researcher, been responsible for its administration.

The MDAS assessment impacted upon family members, leading to conversations with family that revealed their emotional and unmet information needs about delirium. Although small in number, family members' responses provided important information about who the patient was as a person, the timeline of changes and possible contributing causes and highlighted the key role of the family in recognition and comprehensive assessment of delirious palliative care patients (Steis et al., 2012).

When the researcher presented physicians with relevant delirium symptom information about patients, physicians contextualised the observed changes and applied the DSM-5 diagnostic criteria at that point in time. All physicians were observed to have numerous competing demands on their time, and the unit workstations were noisy, crowded and distracting environments. Deliberate efforts, such as pre-arranging ten minutes to meet and having the patient's information and the DSM-5 diagnostic criteria readily to hand, supported the physicians to focus on the patient information and determine if criterion A-E applied (American Psychiatric Association, 2013). These strategies point to how palliative care nurses could similarly gather relevant patient data and succinctly communicate it to their medical colleagues, if they hold a shared goal to confirm patients' delirium status on a daily basis (Brummel et al., 2013).

Uncertainties in applying the DSM-5 diagnostic criteria primarily related to confirmation of Criterion B, since assessment and documentation of patients' baseline attention or cognition at admission was not part of the practice of either site, a known limitation of delirium epidemiological studies conducted in hospital settings (Davis et al., 2013). Another challenge in applying the diagnostic criteria was that for some patients, delirium symptoms had been present for weeks previously, sometimes even months. It is likely some patients in this study would have met all diagnostic criteria for delirium if not for the longer duration of their delirium symptoms. The reality of delirium often persisting for palliative care patients could be met in future by adopting a more inclusive approach to diagnosis, which is to interpret criterion B as *either* acute onset (hours to days) *or* fluctuation in symptoms (Meagher et al., 2014). Such an approach would enable a delirium diagnosis to be assigned (whenever appropriate) to those patients whose attentional and cognitive

changes are persisting rather than acute (Meagher, Adamis, Trzepacz, & Leonard, 2012).

*Strengths and limitations*

There are several limitations to this study. The sample size was small and the point-prevalence method did not identify factors contributing to patients' delirium nor distinguish between incident and prevalent delirium (Bonita et al., 2006). Although initially validated with oncology inpatients, the Nu-DESC requires validation in a palliative care inpatient population and testing of inter-rater reliability in clinical practice (Barr et al., 2013). The MDAS or DSM-5 were not administered for any patients with a Nu-DESC score of < 2. As there is some evidence of the Nu-DESC having low sensitivity in another specialist inpatient population (recovery patients) (Neufeld et al., 2013), there is the possibility patients with delirium were actually missed. There was a very low rate of MDAS completion. Inter-rater reliability measures of application of the DSM-5 were not undertaken and most physicians were not experienced in its use. Conversely, the engagement of palliative care nurses and physicians in the delirium ascertainment processes was important, as it informed of the feasibility of routine use of the delirium measurement method within this care setting. The primary strength of this low-burden observational study was the inclusion of all patients, minimising selection bias, and confirmation of which components of the point-prevalence study methodology were feasible in a palliative care inpatient population.

*Implications for practice and research*

The one in three proportion of patients who screened positive and one in five who met the diagnostic criteria for delirium in this study population lends support for system and practice change within the Australian palliative care inpatient setting, such as currently is being advocated for patients with cognitive impairment in the hospital system more widely (Australian Commission on Safety and Quality in Health Care, 2014). An optimal delirium ascertainment process in palliative care will be supported by routine processes to screen and assess patients' baseline and continuing cognition and attention, using brief, low-burden, observational delirium tools (Australian Commission on Safety and Quality in Health Care, 2014), of which the Nu-DESC is just one example. Other tools which may be considered include the: the Delirium Observation Screening Scale (DOS) (Detroyer et al., 2014) and 4AT

instrument (Bellelli et al., 2014). More validation studies are needed to determine which tools are the most appropriate in palliative care inpatient settings.

There is the also need to investigate the extent of iatrogenic causation of delirium in older palliative care inpatients (Lawlor et al., 2014) and to further build evidence for non-pharmacological and pharmacological interventions for symptom management in palliative care via research inclusive of older patients (PaCCSC Palliative Care Clinical Studies Collaborative, 2014). The ageing of the population urges palliative care nurses and all clinicians to gain knowledge and expertise in the care needs of older people, including skill in assessing patients' cognition and recognising when acute changes have occurred (Soo, 2013).

Daily interdisciplinary communication, especially between nurses and physicians, would support a more focused 'reasoning through' of patients' delirium symptoms and promote timely recognition of delirium and a team response (Brummel et al., 2013). Optimal interdisciplinary practice requires that assessment and team communication take place with patients and family members present and involved, wherever possible (Jessup, 2007); as when cognitive impairment is present at the end of life, the patient's family become even more important in palliative care assessment and decision-making (NSW Health, 2005). Strategies to include family in delirium recognition and assessment may include use of the 'Single Question in Delirium' (SQiD) at the point of admission (Sands, Dantoc, Hartshorn, Ryan, & Lujic, 2010) and other family-targeted delirium tools such as the Family Confusion Assessment Method, which could be tested in palliative care (Inouye; Steis et al., 2012) (Appendix 1.3). Actively engaging family members in delirium care would enable clinicians to better understand the delirious patient as a person, as well as the particular needs of the family (Rosenbloom & Fick, 2014).

Undertaking a larger point-prevalence study is required to confirm this pilot data. Given the small number of inpatient beds (≤ 40) within most Australian palliative care inpatient units, undertaking a true point-prevalence study will require the engagement of a large number of units across a wide geographical area. It is important to continue to test and refine interdisciplinary, low burden measures and processes to ascertain delirium, so that these can become routinised in daily palliative care and integrated within Australia-wide adopted symptom screening systems (Palliative Care Outcomes Collaborative, 2014a).

## 5.7 Conclusion

This chapter reported a pilot study to ascertain the 24-hour point-prevalence of delirium in an Australian palliative care inpatient population, and feasibility and acceptability of the screening, assessment and diagnosis measures used. The Nu-DESC and DSM-5 diagnostic criteria for delirium were feasible and acceptable for use by nurses and physicians respectively, while the MDAS was not for almost all patients with a positive delirium screen. Patients' advanced age and the proportions screened positive for delirium and diagnosed as delirious attest to the need to work towards routinely enacting effective ways to recognise, assess and respond to this distressing disorder within palliative care inpatient settings; and in this, nurses must play a key role.

The following chapter reports a qualitative study which used the Critical Incident Technique to explore in more depth Australian palliative care nurses' recognition and assessment of patients with delirium symptoms.

## 5.8 References

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# Chapter 6: Exploring palliative care nurses' experiences, perceptions and capabilities in delirium recognition and assessment using the Critical Incident Technique

## 6.1 Chapter preface

Chapter five reported a cross-sectional study of delirium within two inpatient palliative care populations in Sydney, Australia. This study confirmed that local delirium prevalence is similar to that reported internationally (Hosie, Davidson, Agar, Sanderson, & Phillips, 2013). Given palliative care patients' advanced age, disease and delirium occurrence, the cross-sectional study also confirmed the need to implement better systems and practice for optimal delirium recognition and assessment. Nurse use of a screening tool, combined with physician administration of diagnostic criteria, has potential utility for improved delirium recognition and confirmation within palliative care clinical practice.

This Chapter reports the key findings of a qualitative study using the Critical Incident Technique, which explores in more depth nurses' delirium recognition and assessment experiences, perceptions and capabilities within Australian palliative care inpatient settings. This qualitative study is situated within the 'action' phase of the knowledge to action cycle, as it examines the local context of care, including the barriers and enablers to delirium knowledge use (Graham et al., 2006). The study addresses the following two research questions:

iii) What are specialist palliative care nurses' experiences, perceptions and capabilities in delirium recognition and assessment?; and

iv) What are the barriers and enablers to nurses recognising and assessing delirium in palliative care inpatient settings?

The qualitative study generated a large volume of data and its findings have thereby been reported in two publications. For conciseness, this Chapter is presented as an amalgamation of the two publications, which are provided in their original form within Appendix 2.

The first research question is answered in the first publication, which reported analysis of participants' recounts of patients' experiencing delirium symptoms and

how delirium was recognised and the patient assessed. These findings are reported in Part 1 of this Chapter, as published in 2014 in the *International Journal of Nursing Studies*, a peer reviewed journal for original research and scholarship in health care and research methods relevant to nursing, midwifery and the health care professions.

The second research question is answered in the second publication. This publication reported nurses' perceptions of the barriers and enablers to recognising and assessing delirium in the palliative care inpatient setting, as revealed by all who participated including those who did not recall and recount a specific patient encounter. These findings were published in 2014 in the *Journal of Pain and Symptom Management*, the official journal of the American Academy of Hospice and Palliative Medicine and the National Hospice and Palliative Care Organization. This international, peer-reviewed journal publishes research and clinical information pertaining to palliative care and pain management. The findings reported in Part 2 of this Chapter are as reported in the second publication.

## 6.2 Publication References

Hosie, A., Agar, M., Lobb, E., Davidson, P., & Phillips, J. (2014). Palliative care nurses' recognition and assessment of patients with delirium symptoms: A qualitative study using critical incident technique. *International Journal of Nursing Studies, 51*(10), 1353-1365. doi: http://dx.doi.org/10.1016/j.ijnurstu.2014.02.005

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## 6.3 Introduction

Improving the capabilities of nurses to recognise and assess delirium in palliative care inpatient settings requires that their perspectives and insights be sought. While two previous studies have explored palliative care nurses' perspectives of caring for patients with 'terminal delirium' (Brajtman, Higuchi, & Mc Pherson, 2006) and nurses' delirium management generally (Agar et al., 2012), little is known about their experiences, views and capabilities in recognition and assessment of this complex and prevalent condition.

The practice gaps of nurses working in a variety of inpatient settings in the recognition and assessment of delirium are widely reported (Agar et al., 2012; Inouye, Foreman, Mion, Katz, & Cooney, 2001; Steis & Fick, 2008; Voyer, Richard, Doucet, Danjou, & Carmichael, 2008). This study sought to move beyond only identification of practice gaps, to also unearth knowledge and practice strengths and potential areas for development of nurses' capacity in a challenging aspect of palliative care, this approach being congruent with the knowledge translation aim and approach of the DePAC project. Practice change requires palliative care nurses to be given opportunities to reflect on their current and potential practice, and to be involved in the generation of solutions to the problem of under-recognition and assessment of delirium (Keatinge, 2002).

To achieve this, a 'solutions seeking' qualitative methodology was used: the Critical Incident Technique (Flanagan, 1954). As described in Chapter three, the Critical Incident Technique is a research method focused on determining solutions for practical problems (Flanagan, 1954; Kemppainen, 2000). It is a flexible and feasible method of researching professional practice that engages participants to share their 'real stories'. The Critical Incident Technique's potential to generate positive change occurs through observing and analysing human behaviour and its outcomes upon a defined problem, to determine which actions are effective, and those that are ineffective or missing (Butterfield, Borgen, Amundson, & Maglio, 2005; Flanagan, 1954; Keatinge, 2002).

## 6.4 Aim

To explore the experiences, views and capabilities of nurses in the recognition and assessment of delirium symptoms in palliative care inpatients.

## 6.5 Objectives

To identify nurses' effective, ineffective and missing practices in delirium recognition and assessment of palliative care inpatients;

To identify nurses' perceptions of the barriers and enablers to their recognition and assessment of delirium symptoms in palliative care inpatient settings.

## 6.6 Methods

The Critical Incident Technique guided the semi-structured interviews, data inclusion and analysis. A clinical vignette of a palliative care inpatient with symptoms of hypoactive delirium was used to prompt participants' recall of a similar incident within their clinical practice. The methods of Critical Incident Technique and clinical vignettes are described in detail in Chapter four. The vignette is detailed in Text Box 6.1.

### 6.6.1 Participants and settings

Registered or enrolled nurses working in clinical roles in Australian specialist palliative care inpatient settings, with at least three months experience in this setting and at least 12 months clinical experience overall, were eligible to participate.

### 6.6.2 Recruitment and informed consent process

Two discrete strategies were used to optimise recruitment and promote inclusion of a heterogeneous sample (Kemppainen, 2000), with invitations distributed via: 1) Specialist palliative care inpatient units; and 2) A nursing social media site (Hosie, 2013). Participants could choose to participate in a telephone or face-to-face interview (Sturges, 2004).

At participating units, nursing managers circulated the participant information and consent form to eligible nurses and notified them of interview times. Nurses who were interested in participating in a face-to-face interview met with the researcher at these times. Written consent was obtained after eligibility was confirmed, provision of information about the study and its voluntary nature, and any questions of nurses answered. Nurses who expressed interest via the nursing social media site were emailed the participant information and consent form, and followed up within a week to ascertain their continued interest in participating. A scripted verbal consent was audiotaped prior to all telephone interviews, with participants forwarding their signed consent post interview.

***Text box 6.1 Vignette***

Mrs X is admitted to your palliative care unit on Monday. She is widowed, aged 81, lives alone and her diagnosis is advanced lung cancer. The reason for admission is for symptom management, as she has escalating pain. She has a son and daughter, but she is unaccompanied by any family or friends at admission. Medical and nursing admission processes are completed. Mrs X was independent with ADLs prior to admission. She shares a four-bed room with 3 other female patients.

Her opioid and adjuvant doses are increased after admission and by day 3 her pain appears to be improving.

Mrs X is a quiet, cooperative lady who displays no signs of agitation, but is noted to be a little vague in her verbal responses. She interacts only occasionally with the other patients in the room. She sleeps for intervals during the day, and is sometimes slow to rouse. Night staff report that she is awake for periods of time each night. When awake, she sits quietly and watches what is happening in the room.

Her son visits her each evening after he finishes work. On the evening of the 4th day of admission, he speaks to the nurse on duty and tells her that his mother has told him that she can see a dead man in the corner of the room, and that it has been there since she arrived on the ward. He also reports that his mother is not as clear in her speech and thinking as is usual for her.

The nurse speaks to Mrs X about this. Mrs X says she has been wondering why no one has talked about this man and that she was too frightened to report what she was seeing, in case people thought she was ‘crazy’. She reveals that she finds the sight of the dead man very disturbing, and is worried she is ‘losing her marbles’. She also reports she is finding it harder to concentrate and remember simple things.

### 6.6.3 Data collection

The face-to-face interviews were conducted within a private room within each unit. The vignette was offered to participants between half to one hour before interviews, with most electing to read this in the private room just prior to their interview commencement. The procedure for telephone interviews varied slightly: the vignette was emailed to participants a couple of hours prior to scheduled interviews, with the researcher unaware of the exact time of receipt. During telephone interviews, the researcher was located in a private office, and participants in their workplace office or home. Consistent with the Critical Incident Technique, the interview was intentionally designed to be of around 20 minutes duration (Kemppainen, 2000). A question route was used for all interviews (Text Box 6.2).

Interviews were conducted respectfully and supportively, so that participants felt safe to disclose incidents that were potentially difficult to share, due to the clinical situation or sub-optimal outcomes (Schluter, Seaton, & Chaboyer, 2008). Participants were reassured that the interview was voluntary and its aim was not to 'test' their knowledge or review their individual performance, but to seek their insights. Interviews proceeded even when participants could not immediately recall a relevant incident, as some participants recalled and recounted an incident during their interview. When incidents were not generating any new behaviours, views, themes or sub-themes, indicating data saturation, a further five participants were recruited and interviewed to confirm data saturation (Flanagan, 1954; Kemppainen, 2000; Liamputtong & Ezzy, 2005).

All interviews were digitally recorded and transcribed verbatim. Field notes were completed immediately after each interview, noting relevant information not captured on tape, summarising key points and recording initial observations and insights (Schluter et al., 2008).

***Text box 6.2 Vignette***

## Introduction to the interview

"Thank you for agreeing to participate. The interview may take about 20 minutes. It will be audiotaped and I may also take some notes during the interview. Is that OK with you?

During the interview I will ask you some questions about your experience in nursing a palliative care patient who has acute changes in their awareness, thinking and perception, with the focus on how nurses recognise and assess these changes. The interview is not meant to be a test, we are mainly looking for insights into what nurses think are the most important things to do when caring for patients with these changes. You might find you feel a bit nervous, or as you recall your experiences it is possible this may bring up some feelings for you. It is OK to not answer all of the questions, or to ask for a break if you need it.

Have you had a chance to read the case study? Are you ready to start now?"

## Interview questions

1. Does this case study reflect a situation you have observed or experienced recently in your own clinical practice?
2. Can you tell me about one particular patient situation in detail?
3. How did you feel about the situation?
4. What did you do?
5. In looking back at that situation, is there anything you would do differently?
6. Thinking about the future, do you have any suggestions for what we as nurses could do to better recognise the changes and manage the situation?

## Conclusion of the interview

"Thank you for your time - I really appreciate your input. Do you have any further comments or questions? Remember, you can contact me by phone or email if you want to discuss the interview or study."

### 6.6.4 Analysis

*Part 1:* In accordance with the Critical Incident Technique all delirium incidents (the units of analysis) were collated into an electronic spread-sheet. Only incidents with: i) an antecedent; ii) a clear and full description of the incident; and iii) an outcome, related to the care of a patient with delirium were included for data analysis (Flanagan, 1954). Any recollections of a potential delirium incident that were vague, generalised or lacking in detail, suggesting either inaccurate recall or insufficient knowledge of the event (Flanagan, 1954), or not providing a clear outcome or information about effectiveness of actions (Bradbury-Jones & Tranter, 2008), were omitted at this point.

Critical Incident Technique has a distinct framework for data analysis that is consistent with other qualitative methodologies (Butterfield et al., 2005). Flanagan (1954) provided three broad recommendations for stages of data analysis, namely: i) determining a frame of reference; ii) formulating categories inductively; and iii) determining level of specificity (i.e. dozens of specific behaviours) or generality (i.e. a few representative behaviours) to report the data (Butterfield et al., 2005; Flanagan, 1954). Interview questions provided the frame of reference for initial recording of data (incidents) into an electronic spread-sheet [AH]. Data analysis was an inductive process, using thematic content analysis (Bradbury-Jones & Tranter, 2008; Glaser & Strauss, 1968; Schluter, Seaton, & Chaboyer, 2011) and began during data collection. Transcripts, field notes and spread-sheets were read and re-read, promoting immersion in the data and close examination of individual incidents. Incidents and behaviours were then compared and contrasted, with a focus on what was occurring in incidents where there was more timely delirium recognition, assessment and intervention, compared to incidents where there was not. The researcher, with guidance from the principal supervisor, undertook theme and sub-theme development. Preliminary categories, themes and sub-themes were discussed with the supervisory team; this analysis helped to refine the key themes and sub-themes to more accurately reflect the data. Congruent with the exploratory aim of this study, themes and sub-themes represent a more general, rather than specific, description of incidents and participants' perspectives.

Part 2: In the second stage of the analysis, an inductive process using thematic content analysis was applied to the qualitative data to gain insights into the

participants' perceptions of the barriers and enablers to their recognition and assessment of delirium symptoms in palliative care inpatient settings (Liamputtong & Ezzy, 2005). Transcripts and field notes were read and re-read, promoting immersion in all data [AH]. Data were entered into an electronic spreadsheet with interview questions providing an initial frame of reference for the multiple codes generated by the data. From this open coding [AH, with independent coding of three random transcripts each by JP, EL], data relating to participants' perceptions of barriers and enablers of nurse recognition and assessment of delirium symptoms were examined closely and categories of patient and family, health professional and system levels identified. Preliminary themes were then generated [AH, JP], and discussed by the researcher team [AH, JP, EL, MA, PD]. Collaborative analysis and verification continued until the final themes were established, that aimed to reflect participants' perceptions of barriers and enablers to nurse recognition and assessment of delirium symptoms in inpatient palliative care settings (Liamputtong & Ezzy, 2005).

## 6.7 Findings

There were 30 participants from nine specialist palliative care inpatient services in three Australian states (Table 6.1). Most participants were female (n=29), working within a palliative care inpatient service located within a major city (n=28) and had over five years specialist palliative care nursing experience (n=20). Twelve participants worked in an advanced practice role, including as a Clinical Nurse: Educator, Specialist, Consultant or Transitional Nurse Practitioner. Of these advanced practice nurses, eight held a relevant post-graduate nursing qualification.

Twenty-five face-to-face and five telephone semi-structured interviews were conducted in late 2012 - early 2013. Duration of interviews averaged 21 minutes (range 7- 62 minutes). All interviews took place during office hours, although participants described incidents that occurred throughout the 24-hour period.

### 6.7.1 Participants' rate of recall and recounting of relevant delirium incidents

Twenty-seven participants stated that the delirium vignette was familiar to them. Of these, 20 provided a detailed description of one or two incidents involving recognition and assessment of acute changes to patients' awareness, cognition and

***Table 6.1 Characteristics of the sample (n=30)***

| Characteristic | Number |
|---|---|
| **Gender** | |
| Female | 29 |
| Male | 1 |
| **Age** | |
| 21-30 | 3 |
| 31-40 | 11 |
| 41-50 | 9 |
| 51-60 | 6 |
| 61-70 | 1 |
| **Position Title** | |
| Registered Nurse | 16 |
| Clinical Nurse Specialist | 6 |
| Enrolled Nurse | 2 |
| Clinical Nurse Consultant | 2 |
| Nursing Unit Manager | 2 |
| Clinical Nurse Educator | 1 |
| Nurse Practitioner Candidate | 1 |
| **Highest qualification** | |
| Certificate | 5 |
| Diploma | 4 |
| Bachelor | 9 |
| Post graduate certificate | 9 |
| Post graduate diploma | 7 |
| **Type of palliative care inpatient service** | |
| Direct care, mixed unit | 17 |
| Direct care, palliative care patients only | 10 |
| Consultative | 3 |
| **Geographical location of workplace *** | |
| Major city | 28 |
| Inner regional | 1 |
| Outer regional | 1 |
| Remote | 1 |
| **Years of nursing experience** | |
| 1-3 years | 2 |
| 3-5 years | 5 |
| 6-10 years | 2 |
| 11-15 years | 6 |
| 16-20 years | 5 |
| > 21 years | 10 |
| **Years of palliative care experience** | |
| < 1 year | 1 |
| 1-3 years | 5 |
| 3-5 years | 4 |
| 6-10 years | 9 |
| 11-15 years | 8 |
| 16-20 years | 1 |
| > 21 years | 2 |

***** Totals more than 30 because one participant worked in more than one geographical area

perception. This generated 28 clearly described delirium incidents that addressed the first study objective.

All participants were familiar with the challenges of nursing delirious palliative care patients and provided insights into delirium recognition and assessment practice in this setting. Thematic content analysis of data obtained from all participants revealed a range of barriers and enablers to delirium recognition and assessment, addressing the second study objective.

## 6.8 Part 1: Identifying palliative care nurses' effective, ineffective and missing practices in delirium recognition and assessment

Thematic content analysis of the 28 clearly recalled and recounted delirium incidents revealed the following two major themes and six sub-themes:

1. The delirium experience:

    i) Patients' delirium: causes, presentations and outcomes; and

    ii) Nurses' concern for the patient and self.

2. Nursing knowledge and practice in delirium recognition and assessment:

    i) Challenges framing and naming observed changes;

    ii) Varying comprehensiveness of assessment;

    iii) Inter-personal relationships and communication are valued;

    iv) Uncertainty and challenges promote desire for learning.

These themes and sub-themes are outlined in further detail below.

### 6.8.1 The delirium experience

*i) Patients' delirium: causes, presentations and outcomes*

The incidents described included a broad range of symptoms and scenarios that were congruent with delirium phenomenology (Meagher et al., 2007), causation (Gaudreau, Gagnon, Roy, Harel, & Tremblay, 2007; Lawlor et al., 2000) and reversibility in palliative care settings (Lawlor et al., 2000; Leonard et al., 2008). Participants attributed patient's delirium symptoms to a range of causes, including often potentially modifiable causes (n=12), such as: infection, hypoxia and medications (opiates, steroids, and an anti-psychotic) (Caraceni, 2013). Complete resolution of delirium occurred in almost half (n=12) the incidents, while in three

incidents the patients' symptoms persisted. Most participants labelled symptoms as 'delirium' (n=14), while few (n=2) actually identified the delirium subtype.

All incidents involved acute changes to patients' awareness, cognition and/or perception. Participants' noted that delirium symptoms were sometimes mild and fleeting, and on occasion developed quickly with escalating severity:

> *"He was alert and orientated on admission, but …yesterday evening, he was starting to become a bit more unsettled and agitated. And then overnight he was quite paranoid and afraid that people were trying to keep him against his will. This morning… he is feeling that we're out to kill him and we're researching on him… and he's starting to use offensive language which is not in his normal personality." (P7)*

Emotional manifestations of delirium, such as anger, agitation or fear were also described:

> *"He was screaming at the top of his lungs… he was holding the buzzer, and he was saying that "That's a bomb" and he's angry with the nurses…" (P17)*

Symptoms were sometimes initially attributed to patient's characteristics such as personality, but in retrospect recognised as having a physical cause which *"... all made a lot of sense afterwards."* (P16), and:

> *"Thinking back…he started with … rambling conversation and not being able to focus, and the vagueness, and other signs that we were just attributing to the medications or he's just a bit strange … I think we made excuses for a lot of the little behaviours earlier on." (P27)*

*ii) Concern for the patient and self*

Overwhelmingly participants expressed feelings of compassion, sadness, empathy or concern for patients experiencing delirium symptoms:

> *"It's distressing to see a patient be fearful of you… they're terminally ill, they might be in pain, and then you add this to their situation where they're lying in bed terrified, frightened and don't want you to come near them…I don't mind how it affects me but it upsets me to see how distressed they are." (P7)*

Patients' distress recalling their delirium experience and their subsequent concerns about their behaviour or mental health meant that participants' concern for their

patients and provision of support continued even when the delirium episode had resolved:

"She knew that she wasn't like quite right: …"*I thought I was going crazy*"… "I know you did but you were perfectly safe, you know?" … "*I know you kept telling me... but I still felt a bit mad"*. (P26)

Participants described feeling an onerous responsibility and isolation *"…it's my duty of care if something happens to her, you know?"* (P30), particularly on evening or night duty:

> *"I was only two years qualified at that stage and I was in charge of the ward that evening as well, and you don't have anyone to consult with …" (P3)*

The incidents provoked feelings of helplessness, fear, frustration, and feeling out of their depth when managing the fluctuating changes associated with delirium

> *"You are wondering is it by talking to the patients, sitting with them and asking them what they are seeing and stuff like that, is that going to help? … Sometimes you feel a bit isolated… a bit helpless… like: "Oh God, what am I going to do here?" (P3)*

### 6.8.2 Nursing knowledge and practice in delirium recognition and assessment

*i) Challenges framing and naming observed changes*

Participants had difficulties framing the neurocognitive changes they had observed and linking them to a potential delirium diagnosis:

> *"Something about this patient, it's very unusual for her…we didn't know what's wrong with her..." (P30)*

Symptoms were not explicitly integrated into a diagnostic or delirium framework:

> *"We were talking about… somebody who came across as a bit confused and a little bit vague, but the consensus with the team was that that was all personality rather than medication induced. I thought that was interesting, I'm like: "How do you figure out that?" (P9)*

Participants often expressed feelings of surprise, puzzlement and frustration when describing the period before confirmation of a delirium diagnosis:

> *"The whole situation you were just feeling "Oh my gosh, what is it with him? How can we help him, why is he feeling like this? Is this part of his personality? … He came in quiet and calm but is he showing his real self now?" …Trying to work out what it was… you were a bit frustrated not being able to solve the problem there and then." (P12)*

Some incidents involved patients seeing deceased family members or heavenly visions; participants were uncertain whether this was delirium or a spiritual or paranormal event:

> *"I had one patient that thought that they could see the gates, St Peter and the gates of Heaven. It was beautiful, she was in a great place, she was so happy and she said: "Can you see it?"…But is that delirium or is that a near death experience? Sometimes you don't know." (P16)*

When it was perceived that there was a non-physical cause for observed symptoms and/or alternative terminology such as terminal restlessness or agitation was adopted, this impeded understanding of delirium:

> *"What I've learnt is that we just don't pick it up. And that we often put everything into one bundle and we call it terminal agitation… I really believe that we really don't understand delirium at all." (P9)* and
>
> *"It's hard to distinguish like delirium and then end-of-life terminal agitation… I don't know how to explain that one." (P30)*

*ii) Varying comprehensiveness of assessment*

Comprehensiveness of patient assessment varied widely, from largely absent to broader assessments that were sensitive, holistic, inclusive of the patient, family and other team members and applied knowledge of potential causes of delirium symptoms (Nursing and Midwifery Board of Australia, 2006). When participants perceived that there was a spiritual or paranormal reason for a patient's report of hallucinations or illusions, such as a certain room on the ward being haunted, or when they attributed patients' perceptual disturbances to 'logical' misinterpretation of shapes or movement of objects in the room, they were less likely to undertake further assessment of the observed symptoms:

> *"She is seeing somebody in her room, but there is nobody there. First I thought she was confused and then I thought … she was watching my reflection from the window… I didn't ask her detail because she (was) dozing off, so I thought "Oh…a dream, half dream"… but I didn't really pay attention or like telling doctor straight away" (P6)*

Participants noted that nurses who labelled patients' presentations as 'terminal restlessness' were also less likely to undertake further assessment and needed prompting to do so:

> *"My (nursing colleague) was using the terminology (terminal restlessness)… And I said, "Have we done a PR? Have we done a bladder scan? Have we checked the urine? … He's a culturally and linguistically diverse gentleman and maybe he's unable to communicate effectively"… The nursing staff got back to me - even though he'd been urinating he had a bladder of 1,000 mls. So they've put a catheter in." (P11)*

In some incidents, a basic physiological assessment of the patient was undertaken before informing the doctor of the observed changes:

> *"The patient is confused and we did all the observations… temperature, and then blood pressure, and then respirations, oxygen saturations… initially I thought she was toxic to the opioids, so I checked the pupils…but she seems okay, she's not opioid toxic…(then) I told the doctor." (P30)*

Participants working in advanced practice roles tended to describe more comprehensive assessment that included family member insights, the patient's phase of illness, goals of care, temporal pattern of symptoms and potential medication causes:

> *"Well …I think it all comes down to a really good and thorough assessment, … knowing that person's story… non-medical and medical, speaking to the family… what was normal for her last week, what have we done since last week, where are we at with our disease process… all of those different things, how are we treating, what are we treating." (P26)*

Although a small number of participants referred to cognition and delirium assessment tools such as the Mini-mental State Examination (MMSE) (Folstein, Folstein, & Mc Hugh, 1975) and the Confusion Assessment Method (CAM) (Inouye

et al., 1990; Ryan et al., 2009), none described their application in their recalled incidents. Two participants stated their hospital's delirium policy gave them guidance on searching for potential physical causes of delirium or delirium symptoms (e.g. laboratory results, physiological measures, urinary retention). Otherwise, participants did not describe using systematic and structured delirium assessment processes.

*iii) Inter-personal relationships and communication are valued*

The most often described and perceived effective strategies for delirium recognition and assessment were development and fostering of relationships and communication between nurses, patients, family members and doctors. Team communication included reporting the symptoms to the doctor and/or the team leader, documenting what was happening for the patient and discussing possible causes and interventions. Participants reported that collaborative communication with doctors supported timely assessment of delirium causation:

> *"We sat down and we talked about the behaviours that had been happening over the last few days… Dr (Name) was saying, "Do you think it might be delirium…maybe we shouldn't be throwing more medication at this man. We have to find out what's going on," and it was the next day they start doing scans." (P27)*

Rapport and shared values between nurses and doctors were considered important:

> *"I then waited until the consultant came in… and spoke to him directly… He actually listened to me…. she ended up on IV antis (antibiotics) and reduction in her opioids and she returned to normal and she went home." (P11)*

Prior knowledge of the person, through an existing nurse-patient relationship or actively seeking to know the person was described as a factor in recognising delirium symptoms:

> *"He'd come into hospital and suddenly developed a lot of agitation and restlessness, which was abnormal for him, and confusion. I had met this man before outside hospital and he was of sound mind." (P10)*

Not knowing the patient meant participants often struggled to make sense of symptoms, such as for this newly admitted patient who spoke little English:

> *"She would lie in her bed really quietly…tucked right under the covers and her eyes were just really wide open, but we couldn't verbally… work out what was wrong with her, but she always had this frightened look on her face and when her family came to visit …they told us that … she felt really scared because she was seeing someone in the room with her." (P16)*

Proactive communication with families elicited further information: *"I rang her daughter and spoke to her…"* (P23). Effective communication further required a preparedness to have sensitive and profound conversations with patients about their delirium experience:

> *"Eventually came out that she was scared about her own death because to her (his) … presence meant that her time was coming closer, she was apprehensive… so she would ask questions like, "How is that going to happen? Am I going to be in pain? Will I be here? Will I be at home? Who will find me?" (P26)*

*iv) Uncertainty and challenges promote desire for learning*

Participants identified that gaps in their delirium knowledge had contributed to their uncertainty, puzzlement and delays in appropriate interventions. Delirium had been largely absent from palliative care education undertaken:

> *"I've done the ABC of palliative care and …advanced symptom management and I don't recall delirium ever coming along as being one of those things that we would look at if a patient was confused or agitated. It has never been brought up…" (P27)*

For some participants, experience of uncertain and difficult delirium incidents had created 'tensions', prompting reflection and subsequent steps to improve their own delirium knowledge and to educate others. The following quote outlines how caring for a man experiencing severe delirium symptoms for several days (eventually determined to be precipitated by steroid medication) had impacted upon this participant's experiential learning and desire to teach other nurses:

> *"I'll always remember that now with this case. That was a good learning…We got the doctor to give us an in-service (after) that, to help us understand more … as a CNS I'm probably going to … look into it more and give education to other nursing staff… so they can be aware of that and in the future if they come across it, they'll know how to deal with it." (P12)*

However, the delirium education participants had sought had not always met their own learning needs:

> *"I went to the delirium study day…. it was really good but I found it was very medical based, I think we need more our level." (P03)*

One participant believed debriefing at the unit level might promote better integration of delirium evidence into nurses' knowledge and practice:

> *"We all know about evidence based practice, but how do we integrate that into the ward?... I think we need more opportunities to debrief and break things down… like: Where was that? Where did we miss it? What was the first trigger? You know, more opportunities to really educate ourselves." (P09)*

## 6.9 Part 2: Palliative care nurse perceptions of barriers and enablers to delirium recognition and assessment

Overall, participants more frequently described what 'helped' rather than what 'hindered' their practice, with 'opposing' current or potential enablers for most barriers identified. For example, while some participants identified a lack of respect from others in the team about their clinical observations as a barrier, a greater number of participants identified that the presence of mutual respect between team members enabled more effective delirium recognition and assessment.

The barriers and enablers to delirium recognition and assessment existed at the patient and family, clinician and system levels, and generated five distinct themes across these three levels:

1. Patient and family level:

    i) Value in listening to patients and engaging families.

2. Clinician:

    ii) Assessment is integrated with care delivery;

    iii) Respecting and integrating nurses' observations;

iv) Addressing nurses' delirium knowledge needs.

3. System level:

    v) Integrating delirium recognition and assessment processes.

These themes are described in detail below, and summarised within Table 6.2.

### 6.9.1 Barriers and enablers at the patient and family level

*Value in listening to patients and engaging families*

Participants acknowledged the challenges inherent in recognising and assessing delirium: *"It's a very difficult symptom, or condition, to diagnose and then treat…"* (P16). Participants believed patients were often reluctant to report their symptoms, due to embarrassment or fear of being seen as 'crazy'. Another perceived barrier was the use of cognitive assessment processes requiring lengthy quiz-like questioning of patients, such as those routinely employed in Australian inpatient settings (Folstein et al., 1975), as these were perceived to be too burdensome for palliative care patients who were frequently frail and fatigued:

> *" "What date is it? Where are you? Do you know this? What year? Who's the prime minister?" ... Let's be a little bit more gentle and understanding when we're trying to pick up any sort of confusion in patients... fatigue is a big factor for our patients, where they just don't have the energy any more to do a lot of the things that we ask them, or to answer the questions." (P16)*

It was suggested that the challenge of recognising and assessing delirium could be better addressed if nurses communicated caringly with patients, to establish rapport and trust. Even though this process also involved questioning the patient, these questions instead centred on patient comfort:

> *"Just communicating with her a little bit more, finding out why she's awake. "Is there anything more we can do? Is something worrying you? Are you uncomfortable?" All those basic things, talking to her, just sitting for a few minutes in the middle of the night beside the bed and just holding her hand." (P13)*

Building relationships meant that even in difficult circumstances patients were more likely to share what they were experiencing, *"People don't talk about that unless they feel confident and trusting in your care*." (P04). Participants also described how they engaged other team members who might spend further time with patients, as a strategy to help them share their concerns:

> *"I'd probably get pastoral care to go and have a chat to her and see if there's anything worrying her… they let the person take the time that they need to talk." (P14)*

Engaging with family members was considered important because their observations provided valuable insights about changes to patients' awareness, cognition and perception, contributing to earlier recognition and assessment of the delirium symptoms:

*"Families often recognise it the most…changes in sleep cycles, not recognising family when they come in or being overly tired…"* (P19); and

> *"Family do give feedback too… if they are in every day they engage with the patient and they say: "Look, there is something different about them today." Even if they are not hallucinating, there is something different: "She's more drowsy" and we act on that too." (P24)*

Participants proactively sought additional information from family, to assist with their assessment process, and asked questions such as: *"Do they say that? Is that normally a problem for them?" (P07)*; and *"Has this happened before? Have they been on these medications for a long time? Is it something new?" (P13)*

Participants identified that barriers to recognising and assessing delirium at the patient level were challenges inherent to the complexity of delirium, patients' reluctance to report troubling changes to their cognition and perceived burden of cognitive assessments requiring lengthy questioning. Enabling factors included establishment of trust and rapport between patients and team members through verbal and non-verbal communication of caring and active engagement of family members in the patient assessment process.

### 6.9.2 Barriers and enablers at the health professional level

*Assessment is integrated with care delivery*

Participants identified time and workload pressures as a barrier to delirium recognition and assessment: *"Because, no way, you don't (have) an hour or two of your day to try and find out what is going on."* (P01). But despite time and workload pressures, participants strived to focus their attention on individual patients during care delivery. This participant believed that it was in making an explicit decision to focus, listen and talk with patients during physical care delivery, rather than be distracted by the many nursing tasks needing completion, by which they came to a better understanding of what was happening for the individual:

> *"You can give a patient a shower in a relaxed, peaceful manner, taking time to have a conversation with them, or you could be like a mad woman and try and do two showers at once and one wash, and be thinking about the next thing …and the patient's talking to you and you're not listening…" (P04)*

Personal contact and interaction with the patient enabled participants to identify changes and conduct ongoing and continuous assessment:

> *"Whilst you're multi-tasking…assessing, talking, picking up cues, learning their verbal and non-verbal cues… you're going in and assessing the patient every time you're interacting with them" (P11).*

Assessing patients for presence of delirium symptoms occurred as an: 'on the run' process, rather than as a discrete, structured delirium assessment per se. For

example, observing patients' capacity to undertake activities of daily living informed participants whether they may be experiencing delirium:

> *"Watching people's coordination and how they're going with feeding themselves…If someone was able to brush their teeth the day before and now today they're not sure what they're doing, something's going wrong, in their basic motor tasks. And why? Question why they're not able to do that today." (P07)*

This included assessing patients' response, attention and awareness during nursing care:

> *"Showering them or getting them ready for a meal or giving them their medication, how they're reacting or not reacting to you" (P14)*

So despite some considering having several patients to care for and many tasks to complete being a barrier to delirium recognition and assessment, most believed that by integrating a continuous observation and assessment process during patient interactions and delivery of care, this enabled them to observe and assess changes to patients' function and the presence of delirium symptoms. However, no participant described recording these observations and assessments within any structured delirium tool; instead, they proceeded to report any concerns to either a more senior nurse or the doctor.

*Respecting and integrating nurses' observations*

Perhaps because of this absence of structured, explicit delirium assessment, some participants indicated that other team members - particularly doctors and other nurses - did not always appear to respect their clinical observations. This in turn appeared to restrain participants from feeling confident and effective in their delirium recognition and assessment role:

> *"We communicate…what's happening with the patients…you make suggestions to doctors or you bring it to their attention…(but) I think the doctors could be a little more respectful of the value of the nurses' information and then nurses more respectful of (our) own opinions" (P04)*

Whereas *"if everyone can work as a team"* (P13) this enabled participants' initial reporting of delirium symptoms and they believed this led to further multi-

disciplinary assessment and improved patient outcomes. Deliberate and conscious efforts to engage with medical colleagues were made to promote teamwork, rapport and mutual respect:

> *"We've just got a new resident and registrar at the moment so it takes a little bit of time to build a rapport, that they can see, "Oh look these (nurses), they're pretty good" ... then you're all aiming for the same thing with the patient. Saying hello to them in the morning, "Hi, good morning, how was your weekend?" Not just all walking past each other." (P13)*

As highlighted earlier, there were examples where relaying observations to the doctor and being listened to contributed to resolution of patients' delirium:

> *"I then waited until the consultant came in in the morning and spoke to him directly…. He actually listened to me… she ended up on IV (intravenous) antibiotics and reduction in her opioids and she returned to normal and she went home." (P11)*

Nursing participation in multidisciplinary team meetings provided opportunities for them to communicate their patient observations:

> *"There's the multidisciplinary meeting which they have once a week…a lot of the nursing staff attend… it's amazing the insights that nurses can give... when you're working with (patients) for eight hours a day…" (P15)*

As did nursing participation in medical ward rounds:

> *"We were doing ward rounds and I relayed that on to the doctor …he worked through a few things and pointed out that she had this delirium…we can interrupt the ward round if we've noticed something over the last 24 hours, any of the nursing staff can have input and say something, that works really good." (P16)*

A daily team meeting facilitated prompt recognition of changes to patients' condition and a multidisciplinary response:

> *"We communicate effectively with ... a full MDT (multidisciplinary) meeting… all week days to get a proper picture of how the patients are travelling, rather than waiting a few days… and we battle those clinical needs and issues as we see them" (P28)*

This finding identifies that for some participants feeling they were not respected or listened to when they reported their observations of changes in patients' awareness or cognition was a barrier to recognition and assessment of patients' delirium. While when participants believed that when they were respected and listened to by other in the team and had regular opportunities to report their observations, this enabled more timely and effective multidisciplinary responses to patients' delirium symptoms. However, team strategies specifically designed for delirium recognition and assessment were not described.

*Addressing nurses' delirium knowledge needs*

Participants acknowledged that gaps in nurses' delirium knowledge was a major barrier to delirium recognition and assessment: *"I just think as nurses we are not trained enough in dealing with delirium"* (P03); and *"I think it's an area where we haven't really even begun to …understand - that's probably what I've learnt about delirium!"* (P09). Even though having cared for many patients with delirium, several participants conceded their own knowledge deficit:

> *"Assessment is usually crucial, but it's just knowing how to assess… I don't know what the questions would be." (P01)*

They also acknowledged that beliefs that a patient's personality or old age explained delirium behaviour was a barrier to prompt recognition: "Don't just think: *"It's old age"*" (P07) and:

> *"How do you get a person to change their thinking from "That's a batty old lady" to "Oh, well there might be something else going on there…"?" (P19)*

This participant highlighted how her lack of knowledge about the potential for steroid medication to precipitate delirium resulted in feelings of bewilderment about a patient's agitated behaviour and delays in recognition of his delirium:

> *"He had just started to go really off and get aggressive, agitated, wanting to get out of here, just wasn't himself. It took us a little while to figure it out but it was actually the dexamethasone… the whole situation you were just feeling "Oh my gosh, what is it with him? How can we help him, why is he feeling like this? Is this part of his personality?" " (P12)*

Participants overwhelmingly believed delirium education opportunities for nurses were needed and that these needed to be tailored to nursing or palliative care practice:

> *"In palliative care courses or when you join the ward …in-services… to help nurses along, educate them a bit more in the area." (P03)*

Most expressed a preference for future delirium learning opportunities that were: linked to actual patient scenarios, relevant to both nursing and multidisciplinary palliative care practice and delivered at the unit or local level:

> *"I think that giving staff the time to personalise it… "This is the evidence based practice" and linking it with a recent case, and saying: "So we need to incorporate this… let's look at this case." (P09)*

Debriefing opportunities around episodes of missed delirium could enable valuable team delirium learning scenarios:

> *"As a team…identify: "OK, so these things happened, but we didn't notice it, we didn't attribute that to the fact that maybe they were delirious" … More opportunities to debrief and break things down and look at the first trigger, like: Where was that? Where did we miss it? What was the first trigger?" (P09)*

This theme highlights that participants readily acknowledged delirium knowledge deficits, erroneous beliefs and limited education opportunities within nursing practice as barriers to optimal delirium recognition and assessment. They also believed their practice could be enabled through development and local delivery of delirium education, particularly using debriefing and 'real-life' patient scenario learning approaches.

### 6.9.3 Barriers and enablers at the system level

*Integrating delirium recognition and assessment processes*

Translation of delirium knowledge into palliative care nurses' routine practice might also be regarded as a systems level factor. For example, despite comprehensive delirium assessment in frail, unwell and elderly patients being a complex, multi-faceted process and availability of delirium clinical practice guidelines (Canadian Coalition for Seniors' Mental Health, 2010; Clinical Epidemiology and Health

Service Evaluation Unit Melbourne Health, 2006; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010), very few participants reported ready access to protocols, guidelines or integrated systems that translated this delirium knowledge into their workplace; in fact, they identified their absence:

> *"Unfortunately the (admission) assessment doesn't ask about delirium or depression…and it's not a daily thing that we screen." (P09)*

In the few settings where delirium guidelines were embedded within hospital as a whole, participants described the value of these documents, for both their own practice and when delivering delirium education to other nurses within their workplace:

> *"The palliative care service itself has come up with delirium guidelines for the palliative patient… (that are) policy for the whole hospital....when I'm doing education I say to people: "This is a copy of this document about delirium, take it away and read it, it's really interesting, it will inform your practice and how you do things." (P21)*

Most participants believed that integration of delirium screening or assessment tools, care plans or a delirium "clinical pathway" (P30) into the inpatient setting would result in better delirium recognition and assessment practices by nurses:

> *"What about a delirium risk assessment tool … for the frail aged particularly... something that we can create as a screening tool that can give an alert system." (P19);* and
>
> *"I think there should be screening in place. I would like to see in the future that there is a really good assessment that we can do…that we can say, "OK, this person possibly is delirious, let's go through the assessment and then we can know for sure." (P09)*

***Table 6.2 Nurse perceptions of barriers and enablers to delirium recognition and assessment in palliative care inpatient settings***

| Level | Barriers | Current Enablers | Potential Enablers | Themes |
|---|---|---|---|---|
| Patient and family | Delirium is difficult to recognise<br>Commonly used cognitive assessment tools can be burdensome for the patient | Establishment of rapport and trust with the patient<br>Seeking family knowledge of the patient's baseline function, cognition and perception | None identified | 1. Value in listening to patients and engaging families |
| Clinician | Time and workload pressures<br>Lack of respect for nurses' observations<br>Gaps in nurses' delirium knowledge and erroneous beliefs<br>Few delirium education opportunities relevant to palliative care | Compassion and concern for patients<br>Conducting assessment during delivery of care<br>Respect, response and integration of nurse observations into team discussions | Develop education resources using palliative care scenarios, deliverable locally and widely | 2. Assessment is integrated with care delivery<br>3. Respecting and integrating nurses' observations<br>4. Addressing nurses' delirium knowledge needs |
| System | Minimal integration of delirium guidance tools | Hospital-wide delirium policy and guidelines, where present | Development and/or integration of delirium guidance tools e.g. risk assessment, clinical pathways, screening tools | 5. Integrating delirium recognition and assessment processes |

## 6.10 Discussion

This qualitative study has identified numerous insights into palliative care nurses experiences, perceptions and capabilities in delirium recognition and assessment, as well as the barriers and enablers to their practice in this inpatient setting.

### 6.10.1 The experience of nursing delirious patients

Similar to other studies exploring palliative care nurses' delirium experiences, this study confirmed nurses working in the palliative care setting experience distress when caring for patients with delirium (Agar et al., 2012; Brajtman et al., 2006; Breitbart, Gibson, & Tremblay, 2002). The predominant feelings nurses' expressed were compassion, concern and empathy combined with worry, frustration, fear, puzzlement, isolation, burden of responsibility and uncertainty: both about what might be happening to the patient and the best way to intervene. These feelings are not limited to palliative care nurses, as another study has found that, nurses regardless of care setting universally feel incomprehension and discomfort when patients are delirious (Belanger & Ducharme, 2011).

### 6.10.2 Recognition of delirium symptoms

Many participants gave clear and nuanced descriptions of patients' multiple delirium symptoms, causes and outcomes, revealing they recognised acute neurocognitive changes had occurred for recalled patients, as well as their sequent impact. Yet most nurses did not immediately recognise the constellation of observed symptoms as delirium. Even with the use of a hypoactive delirium vignette (albeit with perceptual disturbance), most participants recounted incidents involved patients experiencing rapid change and overt behaviours or distress reflecting hyperactive delirium. Caring for these delirious patients' is often challenging, and may be considered a more 'critical incident' and therefore, more readily recognised and remembered by nurses (Breitbart et al., 2002). Alternatively, including hallucinations in the vignette may have prompted recall of a range of delirium scenarios, as perceptual disturbances occur more commonly in mixed delirium (Meagher et al., 2011). Regardless, the incidents recalled by participants were fundamentally representative of the spectrum of delirium presentations that occur in inpatient palliative care settings (Meagher et al., 2007). The incidents reported included more key domains, particularly acute onset, than those described by palliative care nurses in another delirium study (Agar

et al., 2012). The inclusion of a vignette and applying the Critical Incident Technique gave participants an opportunity to give a detailed recounting of a relevant patient incident, which helped generate richer data.

Participants believed that knowing the patient well and communicating with them and their family supported recognition of delirium symptoms. While engaging and listening to patients and families is important, unstructured bedside interactions do not reliably lead nurses to detect delirium (Mistarz, Eliott, Whitfield, & Ernest, 2011). Aside from the challenge of recognising hypoactive delirium, not all patients with this syndrome will be known to nurses, able to communicate verbally or have family available, showing the limitations of using unstructured delirium recognition approaches and sole reliance on patients' and family verbal capacity. In the absence of applying a structured screening and assessment process, nurses are unlikely to identify and precisely document patients' delirium symptoms (Hare, Mc Gowan, Wynaden, Speed, & Landsborough, 2008; Steis & Fick, 2012).

In this study, no nurse reported using a delirium screening, assessment or confirmation tools, despite recommendations for use in high risk inpatient populations (Australian Commission on Quality and Safety of Healthcare, 2015; Canadian Coalition for Seniors' Mental Health, 2010; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010; NSW Agency for Clinical Innovation, 2014). This failure to screen for delirium occurred even though there were delirium tools available in several units and daily symptom screening is routinely undertaken in most Australian palliative care inpatient settings (Palliative Care Outcomes Collaborative, 2014). An unstructured approach to delirium recognition and screening contributes to palliative care nurses' uncertainty, worry and puzzlement about observed symptoms. A failure to screen also frequently delays medical review and the commencement of appropriate intervention(s) designed to reverse and/or reduce the negative impact of delirium for patients and their families (Gaudreau, Gagnon, Harel, & Roy, 2005).

### 6.10.3 Assessment of patients experiencing delirium

Nurses' assessment practice varied considerably, with several incidents of inadequate or no assessment of delirious patients. As identified in Chapter four, comprehensive assessment of patients with delirium symptoms is a multifactorial, interdisciplinary process which includes determination of the patients': physiological status, phase of

illness, wishes and goals of care, level of distress, safety, and spiritual and psychological needs, as well as the contributing environmental factors and support and information needs of the patient and their family. In almost all incidents, the use of structured guidance and a systematic process for the assessment of the patient with delirium was not described and nurses themselves confirmed this absence was a barrier to optimal practice. Compared to bedside nurses, advanced practice nurses were more likely to described elements of a comprehensive delirium assessment. Their awareness of delirium and appropriate care reflects more advanced clinical skills, attainment of post-graduate qualifications and more autonomous roles. Despite these advanced nursing capabilities, none of the participating nurses described undertaking a risk assessment to identify predisposing and precipitating delirium factors (Canadian Coalition for Seniors' Mental Health, 2010; Lawlor et al., 2000; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010). Similarly, no nurses described undertaking a baseline cognitive assessment using a validated tool routinely at admission. Nurses' lack of adherence to recommendation delirium screening and assessment guidelines places palliative care inpatients' at risk of adverse delirium outcomes.

Compounding this reality was nurses' preparedness to attribute patient's perceptual disturbances to 'spiritual' or paranormal causes; and/or to conceptualise delirium symptoms as 'terminal restlessness' and 'terminal agitation'. Both contributed to nurses failing to conduct a comprehensive delirium assessment. Considering the complexity of delirium and requirement for nursing assessment to be comprehensive, systematic and structured, this finding reveals a clear gap in specialist palliative care nursing practice.

### 6.10.4 Knowledge of delirium and its diagnostic criteria

These palliative care nurses had rich experiences of caring for patients with delirium symptoms, yet had varying recognition and assessment capabilities. These findings support Steis and Fick's' assertion that nurses' delirium *knowledge, recognition* and *assessment* are distinct but inter-related concepts, and that nurses' under-recognition of delirium as a syndrome, as opposed to delirium symptoms per se, is due to their limited knowledge of the delirium diagnostic criteria (2008). Any reference to the delirium diagnostic criteria was missing from the practice of these palliative care nurses (American Psychiatric Association, 2000, 2013). A lack of understanding of

the delirium diagnostic criteria no doubt contributes to nurses' puzzlement, worry and continuing frustration, when they were not able to quickly make sense of what was happening for the patient. Limited knowledge and failure to 'frame' patients' symptoms within diagnostic criteria was similarly identified in the previous study exploring Australian palliative care, aged care, aged care psychiatry and oncology nurses' overall delirium practices (Agar et al., 2012). As the delirium diagnostic criteria is predominantly held within the realms of psychiatry (American Psychiatric Association, 2000, 2013), and more recently medicine, nurses are literally 'two steps removed' from this principal knowledge source and have unintentionally been excluded from developing a shared understanding of delirium, recognition capabilities and contributing to the diagnostic process (Hosie & Phillips, 2014). This reality may in part explain why nurses have sub-optimal knowledge of delirium and too often do not promptly recognise and comprehensively assess their patients when they are experiencing this distressing disorder.

*Although establishing any diagnosis is primarily a medical responsibility, nurses are required to develop their understanding and expertise in recognising early signs and symptoms of prevalent syndromes and conditions. A responsibility of registered nurses is to recognise these changes, undertake a comprehensive assessment, communicate the findings to other team members and initiate appropriate patient care (Nursing and Midwifery Board of Australia, 2006; Registered Nurses Association of Ontario, 2003, 2004).* Delirium is intrinsically linked to illness and frailty where the need for nursing care is greatest, so *nurses have a major recognition and assessment role (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013).*

The challenging, emotional experiences of caring for delirious patients were a catalyst for some nurses to seek delirium knowledge and teach others about delirium. However, these nurses also reported a lack of delirium education relevant to palliative care. Nurses working in other care settings similarly report knowledge and education deficits related to delirium (Brajtman et al., 2006; Dahlke & Phinney, 2008; Flagg, Cox, McDowell, Mwose, & Buelow, 2010; Kjorven, Rush, & Hole, 2011).

### 6.10.5 Interdisciplinary communication about delirium

Reflective of gaps in nurses' delirium knowledge, failure to use correct delirium terminology has also been described as an "absence" within nursing delirium

discourse (Kjorven et al., 2011). As previously mentioned, the use of commonly used ambiguous terms such as 'terminal restlessness' or terminal agitation' similarly made it difficult for nurses to conceptualise delirium and link their observations of patients' symptoms to a delirium diagnostic framework. These ambiguous and inaccurate terms then led to inaccurate presumptions of dying, further limiting delirium assessment and considerations of appropriate intervention(s). There is an urgent need for the palliative care community to cease using this imprecise terminology, because of conceptual confusion and potential to miss delirium, which leads to missed opportunities to reverse the syndrome and/or inappropriate interventions (Heyse-Moore, 2003; Hjermstad, Loge, & Kaasa, 2004; Milisen, Lemiengre, Braes, & Foreman, 2005).

Another important finding related to communication is that palliative care nurses engage in discreet delirium observation and assessment of patients while undertaking daily care tasks, such as showering, giving medications and talking with patients. This tacit process may be understood and valued by nurses, but may not be discernible to others in the team, especially if it is rarely documented. Communicating the findings emerging from an unstructured delirium assessment might then explain why some nurses in our study reported feeling a lack of respect for and response to their observations from other team members, which then forms a barrier to effective team approaches to timely delirium recognition, comprehensive assessment and intervention, both at that point in time and likely for future similar patient events. Other nurses have similarly reported feeling dismissed or ignored when reporting delirium symptoms to physicians (Al-Qadheeb et al., 2013; Kjorven et al., 2011), indicating this communication issue is a real barrier to delirium care, and underlining the imperative to better define nurses' role and communication within the interdisciplinary team, tailored to the specific requirements of each speciality or setting of care. The routine use of a delirium screening and/or assessment tool would help in structuring nurses' observations and provide a framework for communicating findings using a language that is universally understood by their medical colleagues (Hosie & Phillips, 2014).

Nurses perceived that the most effective and valued practices in delirium symptom recognition and assessment were knowledge of the patient, collaborative team communication and inter-personal relationships with patients, families and

colleagues, particularly doctors. They remind us of the primacy of positive, caring relationships with others in the provision of person-centred and compassionate end-of-life care, be it with patients, family members or between colleagues (Canadian Coalition for Seniors' Mental Health, 2010; Virdun, Luckett, Davidson, & Phillips, 2015). Proactive communication combined with an empathetic approach is valued by palliative care patients and families, who desire and are reassured by provision of delirium information and a calm, warm and respectful approach that promotes patient dignity (Brajtman, 2003; Greaves, Vojkovic, Nikoletti, White, & Yuen, 2008; Morita et al., 2007). Effective team collaboration, communication and functioning is known to improve processes and outcomes of care, particularly in palliative, chronically ill and frail populations (Abernethy et al., 2013; Tieman, 2007) and is pivotal to team members' health and morale (Palliative Care Expert Group, 2010).

Yet effective recognition and assessment of delirium cannot be achieved solely through clinicians' bedside interactions with patients, however compassionate or present, or respectful team relationships generally. These qualities alone do not sufficiently provide the explicit, honed focus required to distinguish delirium (Mistarz et al., 2011; Spronk, Riekerk, Hofhuis, & Rommes, 2009) particularly when the complexity of palliative care patients' symptom management and holistic care needs is considered.

### 6.10.6 Organisational systems

This study provides further insight into the absence of organisational systems for delirium screening and assessment within palliative care nurses' workplaces, as reported in Chapter four and also as occurs within other inpatient settings care (Eastwood, Peck, Bellomo, Baldwin, & Reade, 2012; Forsgren & Eriksson, 2010; Irwin et al., 2008). It is encouraging that nurses in this study believed adoption of delirium clinical practice guidance and tools in their workplaces would improve practice and patient care outcomes, given that this is a clear gap within the systems of Australian palliative care inpatient units.

### 6.10.7 Strengths and limitations

The strengths of this study include application of Critical Incident Technique, which allowed for brief, focused interviews and identified effective, ineffective and missing practice, and confirming it as a feasible method to obtain nurses' perspectives and

explore their delirium practice. A deliberate strategy was to include all participants' insights relating to delirium recognition and assessment barriers and enablers, consistent with the overall intention of Critical Incident Technique to reveal factors that help or hinder an activity (Butterfield et al., 2005; Flanagan, 1954). Adopting this approach provided additional valuable insights into nurses' views on barriers and enablers to their current and future practice. Including verbatim quotes and the independent coding of six random transcripts by two additional coders during data analysis strengthened the reporting and analytic rigor of the study (Liamputtong & Ezzy, 2005).

A limitation is that the findings of this study may not be transferable to other geographical regions and settings of care. While the sample consists of nurses with varying roles and from several Australian palliative care units and different geographical locations, these nurses self-selected to participate and it is possible their experience reflects the views of nurses most interested in delirium. Almost all participants were female, which is likely to be generally representative of Australian nurses, but another potential limitation of the sample. There were only a small amount of incidents compared to other Critical Incident Technique studies. Yet this is consistent with the exploratory nature of the study combined with the focus on a narrow aspect of delirium care, namely inpatient palliative care nurses' recognition and assessment practices. Similar to previous Critical Incident Technique nursing studies (Bradbury-Jones & Tranter, 2008), a third of participants did not recount a specific clinical incident, despite the use of a vignette to prompt recall. Difficulty recalling a relevant incident may relate to under-recognition of delirium symptoms; alternatively, participants may not have been given or taken sufficient time for recollection. As Critical Incident Technique also relies on participants' capacity to accurately recall and express past events and actions, the recounted incidents may not fully reflect the event or extent of participants' actions. Participants were not directly asked to describe barriers and enablers to their delirium recognition and assessment practice, which may also limit the completeness of the findings.

### 6.10.8 Implications for practice and research

Given the prevalence and incidence of delirium in specialist palliative care settings (Hosie et al., 2013), a "high index of suspicion" by nurses is warranted (Le Grand, 2012, p. 585). It requires making delirium screening on and during admission

routine practice, particularly when potentially delirium inducing interventions are introduced, such as introducing and/or titrating opiates, benzodiazepines and or steroid medications (Caraceni, 2013; Hosie et al., 2013; Rao, Ferris, & Irwin, 2011). Nurses must have equitable and timely access to evolving delirium knowledge and diagnostic criteria (American Psychiatric Association, 2013), and their translation and integration into everyday palliative care clinical practice and systems is a critical first step towards developing nurses' delirium recognition and assessment capabilities (Registered Nurses Association of Ontario, 2004). Investigation as to whether a routine structured delirium screening and assessment process supports palliative care nurses to recognise, assess and communicate patients' delirium symptoms is also required (Detroyer et al., 2014).

Implementation of structured delirium processes into routine palliative care nursing practice requires mindfulness of the need to choose tools that are: appropriate and low-burden for the majority of palliative care patients; inclusive of the observations and input of family members; incorporative of nurse observations; brief and comprised of easily memorised components, that can be rapidly internalised and applied by nurses during each patient interaction. As highlighted previously, tools meeting all or some of these criteria include: the 4AT (McLullich, 2014); the Nu-DESC (Gaudreau, Gagnon, Harel, Tremblay, & Roy, 2005); CAM-ICU (Ely et al., 2001); short-, 3D- or bCAM (Han et al., 2013; Hospital Elder Life Program, 2015; E.R. Marcantonio et al., 2014); SQiD (Sands, Dantoc, Hartshorn, Ryan, & Lujic, 2010); the DOS (Detroyer et al., 2014)and RADAR (Voyer et al., 2015). Apart from the DOS, none of these tools have been validated in palliative care populations, so further research testing their feasibility and reliability in this setting is required (Australian Commission on Safety and Quality in Health Care, 2014).

Effective palliative care requires optimal collaboration and respectful and effective communication between team members via shared knowledge, language, tools and daily discussion, to improve delirium recognition, assessment and intervention in the palliative care setting (Balas et al., 2012; Brajtman et al., 2008; Vasilevskis et al., 2010). Having a common language is crucial to improving palliative care patient outcomes (Abernethy et al., 2013; Phillips et al., 2006) so there is great potential benefit in building team members' delirium knowledge (Brajtman et al., 2008), adopting a shared delirium language shaped by the DSM-5 criteria (American

Psychiatric Association, 2013) and creating routine opportunities to explicitly discuss patients' delirium status. For example, in the ICU setting whole team interventions for delirium care have demonstrated that when nurses adopt the role of performing routine, structured, systematic delirium assessment processes, this better informs team decision making around patient care needs (Balas et al., 2012). Delirium care exemplars such as these inform us of how we might develop similar strategies within palliative care practice.

Similar to other studies (Brajtman et al., 2006; Dahlke & Phinney, 2008; Flagg et al., 2010; Kjorven et al., 2011), nurses in this study desired more delirium education and preferred that it be linked to real patient scenarios, relevant to nursing and interdisciplinary palliative care practice and delivered at the unit or local level. Further investigation of palliative care nurse delirium learning needs is required. Advanced practice nurses have an important role in defining, teaching and diffusing exemplar delirium practice within palliative care units. Improvement in nurses' delirium knowledge, confidence, documentation and detection of delirium has been demonstrated across elderly acute, post-acute and palliative care inpatient settings through educational and practice change interventions (Akechi et al., 2010; Brajtman et al., 2008; Li, Giles, Dumont, Day, & Higgins, 2009; E. R. Marcantonio, Bergmann, Kiely, Orav, & Jones, 2010) and this will be an important component of practice development. It is essential that future delirium in palliative care educational initiatives be evidence-based in content and delivery methods (Brajtman et al., 2008; Phillips, Shaw, Heneka, Hickman, & Lam, 2013). For example, novel online spaced learning delivery methods impact on knowledge, practice and patient outcomes, and therefore offer promise for changing entrenched delirium practices (Phillips et al., 2013).

## 6.11 Conclusion

The findings of this study reveal that palliative care nurses are striving to provide effective, compassionate and person-centred care to patients experiencing delirium symptoms, but that they are doing so with limited delirium knowledge and educational opportunities and in the absence of structured screening, assessment and interdisciplinary team processes. These nurses also identified how their delirium practice might be developed. Given the prevalence of delirium experienced by palliative care patients, addressing the multi-level factors that impact on nurses'

ability to optimally recognise and assess patients' delirium symptoms is critical to advancing delirium care in this specialist setting. This study provided valuable information about the numerous opportunities to improve nursing and interdisciplinary team palliative care practice. Through development of delirium systems, practice and knowledge palliative care nurses' own professional support needs may be addressed, and their compassionate desire to help delirious patients better achieved.

The following Chapter reports the final study of the DePAC project. This focus group study explores palliative care nurses' perceptions of the feasibility of integrating one delirium screening tool, the Nu-DESC, into their routine clinical practice.

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# Chapter 7: A focus group study of nurses' perceptions of the Nursing Delirium Screening Scale

## 7.1 Chapter preface

Chapter six reported the findings of Study four which used the Critical Incident Technique to explore the experiences, views and capabilities of nurses in recognising and assessing palliative care inpatients' delirium. This study confirmed the many opportunities to improve nurses' recognition, assessment, communication and knowledge of delirium, at the patient and family, clinician and systems levels

Chapter seven reports the final study of the DePAC project. This was a focus group study exploring nurse perceptions of the feasibility of integrating the Nu-DESC into their routine clinical practice. The study was positioned within the action stage of the knowledge to action cycle, as it is concerned with assessing local barriers and enablers to knowledge. The two research questions this study addresses are:

What are the experiences, views and capabilities of nurses in recognising and assessing palliative care inpatients' delirium?

What are the barriers and enablers to nurses recognising and assessing delirium in the palliative care inpatient setting?

This chapter presents an online published peer-reviewed journal article with minor amendments. The Journal of Clinical Nursing is an international, scientific scholarly journal that encompasses all aspects of nursing practice. The journal aims to develop and share nursing knowledge, and thereby promote the discipline and practice of nursing. The publication is aimed at a nursing audience, and also has relevance for the palliative care interdisciplinary team. A copy is provided in Appendix 2.

## 7.2 Publication reference

Hosie, A., Lobb, E., Agar, M., Davidson, P. M., Chye, R., & Phillips, J. (2015). Nurse perceptions of the Nursing Delirium Screening Scale in two palliative care inpatient units: a focus group study. *Journal of Clinical Nursing*, n/a-n/a. doi: 10.1111/jocn.12925

## 7.3 Introduction

By exploring the feasibility of the routine use of the Nu-DESC in the palliative care inpatient setting insights can be gained into how delirium recognition and assessment by nurses can be improved. The Nu-DESC was chosen as the tool to explore in this study because, as previously described in Chapter five, this screening tool had been available to nurses at the study sites for a three-year period for research purposes (Agar, 2010) and they had received didactic and one-on-one teaching on its application (Gaudreau, 2013; Gaudreau, Gagnon, Harel, Tremblay, & Roy, 2005). Nurses were not mandated to use the Nu-DESC within the previous research studies or their clinical practice, but had been encouraged and supported to do so by site investigators and research nurses. Despite its ready availability and their training in its use, they had not adopted the Nu-DESC in routine clinical practice.

In order to better understand if the Nu-DESC was a feasible screening tool for inpatient palliative care to use on a routine basis, we sought nurses' perceptions of its use.

## 7.4 Aim

To explore nurses' perceptions of the feasibility of integrating the Nursing Delirium Screening Scale into practice within the inpatient palliative care setting.

## 7.5 Methods

### 7.5.1 Design

A focus group method was chosen to obtain individual and collective views of nurses working in these two units. It was anticipated that focus groups would promote conversation and interaction between nurses about their experiences and perceptions of using the Nu-DESC and thereby reveal the extent of diversity of opinion about delirium screening and follow up care within the palliative care unit.

### 7.5.2 Setting and participants

The study took place in two palliative care units, each situated within sub-acute hospitals in Sydney, Australia. Each unit provides multidisciplinary care for patients with a life-limiting illness who require symptom management, respite and/or terminal care. All nurses working in the participating units who had used the Nu-DESC were eligible to participate.

### 7.5.3 Informed consent process

Unit managers informed nurses of the study the week before the focus groups via usual communication channels; for example, email and a flyer on staff notice boards. Immediately prior to the groups the unit manager reminded nursing staff about the study and introduced the focus group facilitator. The facilitator gave verbal and written information about the study to nursing staff, who were given the opportunity to ask questions and discuss the implications of participation. Nurses who elected to participate provided written consent. Participation was voluntary, with no negative consequences if nurses choose not to participate.

### 7.5.4 Data collection

To minimise disruption to nurses' workday and patient care focus groups were designed to be of short duration (i.e. less than 30 minutes). A brief semi-structured question route was developed (Table 7.1) and integrated into a focus group schedule and field note form. Focus groups were timed to occur immediately after nurses' verbal handover (0730 and 1400) to maximise participation and capture the views of nurses working on all shifts. There were two facilitators: the researcher and a research nurse, who separately undertook two focus groups at each site.

Participants were assigned a unique code ('P*n'*) to distinguish each in the documentation and reporting of the study and maintain their confidentiality.

***Text box 7.1 Focus group question route***

1. Can you please tell me your thoughts about using the Nu-DESC to screen patients for delirium symptoms?
2. What are your thoughts about the acceptability of this delirium screening tool?
3. Is routine use (each shift) of the Nu-DESC feasible in this palliative care setting?
4. Did using the Nu-DESC influence your practice?
5. Did using the Nu-DESC influence the care your patients received?
6. Does anyone have any further thoughts or comments?

### 7.5.5 Data analysis

Digital recordings of focus groups were transcribed verbatim. The transcript, field note observations and key messages were used to develop codes, categories and themes inductively using thematic content analysis (Liamputtong, 2011). No qualitative data analysis software was used; instead, participants' quotes were cut and pasted into a word document table and through immersion in the data, categories and themes were developed. These were then reflected upon and discussed with the principal supervisor, resulting in conceptual refinement and development of higher-level themes. The research team then together considered and discussed these emerging themes with further refinement occurring to ensure that reported themes accurately reflected participants' perceptions (Liamputtong, 2011).

## 7.6 Findings

Four focus groups were held during January – February 2014. Twenty-one nurses participated including registered (n=16), enrolled (n=3) and assistant nurses (n=2). The number of participants in each group ranged from four to seven. Groups had a mean duration of 17.5 minutes (range 15-20). Each was digitally recorded and then transcribed by facilitators.

Three major themes arose from the data and are described below.

### 7.6.1 Delirium screening using the Nu-DESC is feasible, but then what?

Overwhelmingly, participants agreed that the Nu-DESC was a brief and easy to administer tool: *"It takes two seconds to do really"* (P8) and simple to use: *"It's simple for me, you just have to tick nil or one or two if there's any presentation at that time."* (P12) Most believed the Nu-DESC was feasible in their unit and corresponded with existing daily symptom screening processes and checking of vital signs: *"It's like doing obs! I think it's feasible" (P18).*

This participant reported that the Nu-DESC had helped them to recognise changes in the patient's condition and intervene for their safety:

> *"It helps identify people who have delirium, and putting early interventions in. There was a patient over the weekend: he was settled when the shift started, but towards the end of it, he was getting confused, agitated. I recognised that this was happening…we put a mattress on the floor, the bedrails down, so he didn't fall. (P11)*

The Nu-DESC also supported documentation of their observations of patients' symptoms: "*It provides our assessment down on paper."* (P5).

Yet others were uncertain of the purpose for delirium screening: *"What is the goal of this anyhow? To put them on some medication, when you find out that they're delirious?"* (P19) or if it had activated them to respond: *"I don't know if I actually did a urine test or anything else"* (P7). Consistent with uncertainties and variance in follow up care, participants expressed a need for practice guidance, preferably that which could be easily carried on their person such as a small laminated card:

> *"It would be nice to have a checklist. For example: infection, do a urine test, blood sugar, pain, bowels importantly, oxygen saturation, hydration... because we can't remember everything." (P9)*

It was suggested that better guidance might help nurses to first consider a range of possible interventions for the patient, rather than hastily resorting to medication:

> *"If they score two or more, have you thought/considered this? Rather than throw Haloperidol at them." (P8)*

Significantly for follow-up care it appeared none had engaged directly with medical colleagues about the Nu-DESC or discussed the finding of the screening process with

the patient's treating doctor: *"I'm not even sure if they did look at it. They might have just glanced at it, but not really approached us to say: "Why did you give this score?"* (P11). Participants also wondered how a nurse-completed delirium tool could impact upon their medical colleague's clinical practice:

> *"It would be good to know how the doctors would use the screening tool… Would the screening tool be used for treatment? Would the doctors' review it? If we were going to use it everyday in our practice…what's it going to do, how is it going to be used?" (P12)*

So while participants perceived the Nu-DESC to be an easy, brief tool for use in their unit and therefore feasible, it did not automatically translate to them feeling confident about the actions required nor leads to a consistent approach in follow-up delirium care. Participants expressed needing additional help to navigate this complex process including having readily accessible practice guidance and strategies to better communicate with the treating doctors.

### 7.6.2 Nuances, ambiguity and clinical complexity of using the Nu-DESC in palliative care

Although participants perceived the Nu-DESC to be easy and brief its use highlighted the nuances, ambiguities and complexities of delirium recognition in a palliative context. Participants described a range of practical challenges of using the Nu-DESC, such as determining the best time to complete the scoring during the shift and: *"If there are changes in the patient, do we have to score it again?"* (P16). Concerns were also raised about a perceived disconnect between scoring at the end of the shift and trying to make sense of and respond to patients' symptoms and distress during the shift:

> *"Using the form at the end of the shift, during the shift we're still addressing the issues as they come along. So whether they're incontinent of urine or restless or need pain relief or something for agitation…the form isn't really (guiding action)… For me, it didn't really correlate yet with practice. (P12)*

Participants asked: "*How do you score if they are unresponsive, or unconscious?"* (P11). They also requested clarification of 'psychomotor retardation' (Item 5) because of the frequency of palliative patients' diminished function:

> *"Psychomotor retardation…people were putting zero, even if there is a change in their normal function of daily living, whereas I was thinking: 'No, it should be one or two', on my shift anyway. I think there were different perceptions about that question. Because we see so much of that in our patients, don't we?" (P12)* Others: *"Yeah, yeah."*

Participants expressed the need for*: "…clarity on how to do the assessment itself. People needed more understanding of how to do this."* (P11)

Participants anticipated seeing medication-induced confusion or drowsiness and were either uncertain whether these adverse effects counted towards the Nu-DESC score or indicated that they shouldn't:

> *"Our patients in palliative care can be quite drowsy at certain times, depending on their medications. For example, does the patient respond appropriately, or are they making sense? They may not, but this is because they've had drugs. It's hard to clarify and have an objective score. (P6)*

There were other uncertainties about the objectivity of the Nu-DESC:

> *"The problem is, it's a variable. An individual nurse's perception of what they think is the score. You mightn't necessarily come up with the same score in the same situation. Sometimes I find following on from someone else's shift, I wonder about their scores." (P2)* and *"I agree with that." (P3)*

Participants were aware of the complexity and impact of patients having co-morbidities, prior cognitive impairment and/or irreversible disease progression. They found: *"Sometimes it's hard to distinguish as to whether its dementia or delirium"* (P6). In this palliative care setting, several debated the value of ongoing delirium screening for all patients: *"Some delirium's not treatable. It's disease related, so you can't treat it… what do you do when they are scoring all the time?"* (P20). While others argued strongly against presumption that delirium is inevitable and 'not treatable' as exemplified below:

> *"But for a large proportion, the majority are treatable. Like that gentleman we had on the weekend in room 21, he was wandering, he obviously had delirium that wasn't recognised." (P21)*
>
> *"But he has got vascular dementia." (P18)*

*"Yeah, but he'd changed. He started to wander." (P21)*

*"He's got disease progression." (P20)*

*"Yeah, but he's much more alert on Monday than he was on Saturday. Just because someone's got dementia doesn't mean they don't have delirium. That's why sometimes we don't capture them, if they have a cognitive impairment." (P21)*

*"That's why it is hard to recognise, when it's a delirium…dementia, and then cerebral mets." (P18)*

*"But if it's a change in their normal behaviour, wouldn't you agree it is a change on top of what they've already got? They could be reversed." (P21)*

This conversation revealed divergent views about the opportunity for active interventions to relieve delirium symptoms and distress and that under-recognition and/or misattribution of delirium symptoms continue to delay response.

### 7.6.3 Implementing structured processes requires firmer foundations

Without a firm foundation of knowledge about delirium and the 'how and why' of structured processes for recognition there is likely to be a degree of resistance to the routine adoption of a tool such as the Nu-DESC.

Despite training and intermittent use misinterpretation of the purpose of the Nu-DESC was common, with several participants viewing it primarily as a monitoring tool for a suspected or established delirium. This consequently prejudiced their willingness to apply it for all inpatients: "*Use on a patient who had been identified as possibly having a delirium"* (P5) and: *"Not sure about its usefulness as a daily thing for the whole ward. Some people don't need it."* (P7) Blurring of the distinction between screening, severity monitoring, comprehensive assessment and diagnosis similarly resulted in hesitancy to advocate for routine use due to concern that a positive screen might wrongly attribute delirium to patients who were not delirious:

*"We have to be careful not to make assumptions. Their behaviour may have changed because they are incontinent of urine or want a drink of water or they're uncomfortable, in pain…" (P12)*

Willingness to personally apply the Nu-DESC was influenced by participants' perceptions of their own need of a delirium recognition tool. Most acknowledged

their delirium knowledge and practice required support. These participants expressed how the Nu-DESC had increased their overall awareness of delirium, including the hypoactive subtype:

> *"It's made us all more aware of the diagnosis of delirium. I used to think that it was another thing that people got when they are dying, but now I realise that you don't have to get it, it might be from infection or some other cause or a medication…there are different causes that can be fixed." (P7)*

> *"You know the one: silent, inactive delirium, the quiet one… I never heard of that delirium. Hypoactive delirium was something new to me." (P9)*

Having shorter duration of nursing experience, this participant appreciated a structured tool:

> *"I'm a new grad (graduate), so coming on… the tool made it easy to identify the new (symptoms)." (P11)*

In contrast, some participants (n=4) expressed that 'good' nurses did not need the Nu-DESC to recognise when patients were delirious: "*Probably a good assessment to have on board, but any nurse worth their salt doesn't actually need that assessment to work that out."* (P2) A combination of pride and great confidence in one's nursing capabilities are potential barriers to implementing the Nu-DESC as a routine screening tool:

> *"Experienced staff, who have had a lot of exposure to delirium, you would have done it routinely….you identify them without the tool. I think senior staff, good staff, do it routinely (as) part of your nursing care…you don't need the tool." (P5) Other: "I agree"*

Yet these participants did acknowledge its potential value for less experienced nurses and/or to provide a record of changes in patients' status over time:

> *"I suppose in the context now that we move between the wards and that we have different patients, it's a good sequential thing that we can look back on" (P2)*

> *"…for junior staff and students and new staff, I think it's a good way for them to identify what is delirium." (P5)*

## 7.7 Discussion

This study provided valuable insights into nurse perceptions of the Nu-DESC and delirium practice in inpatient palliative care. It identified further opportunities to strengthen nursing delirium recognition and management practices. While nurses perceived the Nu-DESC to be easy and brief, similar to other symptom screening and instrumental in raising their awareness of delirium, there were numerous knowledge related barriers to its adoption. Namely, varying understanding of: the screening intention of the Nu-DESC, the value of structured delirium recognition processes (even when delirium is not reversible) and interventions required following a positive delirium screen. These knowledge gaps were balanced by nurses' desire for greater guidance in optimal delirium care which seemed to be a major driver for their willingness to adopt the Nu-DESC into clinical practice, even for those who believed their own experience and skill were sufficient to recognise delirium.

However, enthusiasm for routine implementation of the Nu-DESC was diluted whenever there were misunderstandings of its intended purpose and the difference between screening, assessment and diagnosis. Belief that nursing skill and experience is sufficient to recognise delirium also impacted on readiness to adopt a screening tool into one's own practice. Yet, as highlighted in Chapter six, being an experienced and/or knowledgeable nurse in a specialist area of care does not of itself ensure adequate recognition of delirium (Mistarz, Eliott, Whitfield, & Ernest, 2011). Nurses who disdain the value of a tool will need to be encouraged and supported while they re-learn their approach to delirium recognition. More newly graduated nurses in contrast were most accepting of the Nu-DESC, suggesting their recent nursing education had instilled that symptom screening and assessment was a structured and systematic process. It may also have been easier for newly graduated nurses to acknowledge their need for learning than those with longer duration of nursing experience. Improving the delirium recognition and assessment capabilities of nurses will therefore not only be supported through continuing practice development for the existing workforce but by strengthening the delirium learning content in undergraduate nursing curricula.

Enthusiastic nurses of all levels of experience can be supported to act as 'change champions' to promote adoption of delirium screening (Shaw et al., 2012). For example, a successful approach to improve delirium recognition in an inpatient

trauma unit involved the training of junior nurses to provide their more experienced colleagues with real time feedback about completion of the Confusion Assessment Method (CAM) (Inouye et al., 1990). The intervention was well received, resulted in fewer discrepancies between oral and documented reports of patients' mental status and increased the number of patients identified as delirious (Waszynski, Levick, Andrews, Stowe, & Reagan, 2014).

Nurses requested more tailored guidance for use of the Nu-DESC with palliative care patients. Guidance would address nurses' uncertainty about scoring, particularly of the psychomotor retardation item, when patients are not fully responsive or functioning due to medications, pre-existing cognitive impairment or being in the dying phase. The original validation study stipulation of "unusual" and "taking into account the patient's medical condition" requires precaution in a palliative population (Gaudreau, et al., 2005). Nurse perceptions that drowsiness and/or inappropriate patient response arising from medications ought not count towards Nu-DESC scores reflect an underlying belief that adverse drug effects are normal, acceptable and/or innocuous. Assuming that reduced responsiveness and functioning is usual or expected for palliative care patients is similar to erroneous attitudes that cognitive impairment is a normal part of ageing (Mc Carthy, 2003). Assumptions that behaviour disturbance is usual for patients with a dementia also compounds under-recognition of delirium (Fick, Hodo, Lawrence, & Inouye, 2007). Attitudes such as these are major barriers to delirium recognition and timely management of iatrogenic or reversible precipitants. For instance, delayed responsiveness may herald that a patient is dying, or alternatively, that a frail, elderly and previously highly functioning patient is experiencing a severe adverse effect of a new analgesic. While these patients may have similar initial presentations and Nu-DESC scores the underlying cause, significance and management will vary according to each patient's circumstances and are best informed by the outcomes of a full assessment and team and family consultation (Australian Commission on Quality and Safety of Healthcare, 2015).

Nurses in this study reported a disconnect between knowing something was amiss with their patient, wanting to act to relieve patient distress and assigning a Nu-DESC score at the end of a shift. This indicates that definitive and immediate delirium confirmation strategies may be required to augment the Nu-DESC. For example, the

conjoint use of a dichotomous tool such as a briefer versions of the CAM (Ely et al., 2001; Han et al., 2013; Hospital Elder Life Program, 2015; Marcantonio et al., 2014). Point-of-care access to the DSM-5 delirium diagnostic criteria may also support nurses and teams to more accurately and confidently interpret a positive Nu-DESC screen and take immediate positive action.

Similarly to the finding of varying levels of assessment in Study four, nurses revealed varying responses to a positive delirium screen, including: no action, instigating team discussion of observed changes and putting safety measures in place, and instigation of pharmacological interventions before non-pharmacological interventions were trialled. This last approach was disquieting, because of possible missed iatrogenic or reversible causes and there being limited evidence of effectiveness for any class of medication for delirium in this population (Agar et al., 2015; Bush et al., 2014). Yet nurses also apprehended that screening is only one step in delirium care and they wanted readily accessible guidance for the follow-up care of patients with a positive Nu-DESC. This again urges the building and integration of delirium evidence in this care setting (Lawlor et al., 2014).

As reported in Studies two and four, nurses revealed that a united team approach to delirium care was missing (Hosie, Agar, Lobb, Davidson, & Phillips, 2014; Hosie, Lobb, Agar, Davidson, & Phillips, 2014). Nurses were uncertain if doctors had noticed Nu-DESC scores and/or what action they would take for a positive delirium screen, and they wanted to be assured of their involvement. Of note, none mentioned how good inter-disciplinary teamwork required nurses to take responsibility to alert doctors to changes in the patients' status (Nancarrow et al., 2013). This finding may reflect that these nurses' had perceived that the primary purpose of using the Nu-DESC was for research purposes and therefore they had not thought it necessary to take any clinical ownership of delirium screening within their units. As sub-optimal team communication about delirium is a re-occurring barrier to optimal care within the literature (Al-Qadheeb et al., 2013; Kjorven, Rush, & Hole, 2011) purposeful interdisciplinary communication and collaboration will be key to the success of future knowledge translation initiatives, and in these team deliberations nurses must take an active role.

### 7.7.1 Strengths and limitations

The limitations of this study include the convenience sample. Participants worked within just two metropolitan Australian palliative care unit, so findings may not be transferable to other care settings. Due to timing and funding constraints only four focus groups were planned and although there was consistency in participants' responses, data collection was not continued for the express intent of confirming data saturation and confirmation of themes. No data was collected on individual participants' duration of palliative care experience or Nu-DESC usage. Overall, these nurses had only used the Nu-DESC intermittently with potential for further insights had there been greater regularity of use. However, obtaining these nurses' perceptions was an important activity within the knowledge translation process and provided valuable information for the design of future delirium recognition and assessment interventions in this setting. The strength of this study is the inclusion of nurses' voices about an aspect of delirium care for which they are responsible and can make a positive contribution towards.

## 7.8 Conclusion

Nurses working in these two Australian palliative care units perceived the Nu-DESC to be an easy and brief delirium-screening tool that raised their awareness of delirium. They were largely willing to adopt into practice. However, investigation of the psychometric properties of the Nu-DESC and other delirium tools in the palliative care setting is required prior to advocating for routine use. Successful implementation and effective delirium screening in this setting will require not only the use of a feasible and validated tool but also a multifaceted approach that includes nurse education and the tailoring of tools and clinical practice guidance to the context. Palliative care nurses must furthermore become more active leaders and collaborators within their interdisciplinary teams for effective delirium practice change to be achieved.

The following chapter is the final chapter of this thesis. Chapter eight integrates the data from the five DePAC studies to answer the research questions and proposes a theoretical explanation for the problem of delirium under-recognition in the palliative care inpatient setting. The recommendations, significance and limitations of the DePAC project are outlined.

## 7.9 References

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# Chapter 8: Conclusion

## 8.1 Introduction

The catalyst for the DePAC project was a growing awareness of the delirium evidence-practice gaps in palliative care inpatient settings, and opportunities to improve patient outcomes by building nurses' delirium recognition and assessment capabilities. The prevalence of delirium in the palliative care inpatient population demands system and practice reform. Under-recognition of this serious neurocognitive disorder posited knowledge translation as a fitting framework to identify and address nurses' recognition and assessment evidence-practice gaps. Exploration of nurses' delirium experiences, capabilities and workplace organisational systems identified opportunities to strengthen delirium practices in this specialist inpatient setting.

This concluding Chapter integrates data from the five studies reported in this thesis. Meta-inference of the data proposes an expansion of theoretical understanding of the problem of delirium under-recognition and assessment in inpatient palliative care settings (Cameron, 2009). This mixed methods integration process enables all of the DePAC project's research questions to be answered. Emerging from the data integration process is a series of recommendations to address palliative care nurses' under-recognition and assessment of their patients' delirium.

The DePAC project was concluded at a time of promise for improved hospital care of patients with or at risk of delirium, as the Australian Commission on Quality and Safety of Healthcare finalises a new national delirium clinical care standard (Australian Commission on Quality and Safety of Healthcare, 2015). The significance of the DePAC project to nursing and interdisciplinary practice within the palliative care unit is described in the context of the potential of this high-level organisational direction. The limitations of the DePAC project are also outlined.

## 8.2 Key findings

The first four DePAC project questions are answered in the following sections. The ultimate research question: '*What is required to improve the capabilities of nurses to recognise and assess delirium in palliative care inpatient settings?*' is addressed through integration and meta-inference of the data and answered later in the Chapter.

### 8.2.1 Question 1: What is the epidemiology of delirium in the palliative care inpatient population?

The DePAC project has confirmed that palliative care inpatients are primarily a geriatric population at risk of delirium, and for whom it occurs frequently. This doctoral study identified that almost one in five (19%) Australian palliative care inpatients had a confirmed delirum diagnosis within one 24-hour period (Hosie, 2014). The palliative care inpatient population in this study were older (X 74 years) when compared to both the Australian inpatient population overall (X 53.9 years), as well as the study population reported in the earlier systematic review (X 66.24 years) (Australian Institute of Health and Welfare, 2014; Hosie, Davidson, Agar, Sanderson, & Phillips, 2013).

Studies screening patients at least once daily reported higher incidence (33-45%) compared to studies where daily screening was not routinely undertaken (3-7%) (Hosie et al., 2013), indicating more frequent delirium screening results in more case finding and potential benefit of daily delirium detection processes in clinical practice (Gaudreau, Gagnon, Harel, & Roy, 2005). Differing study measures, including varying regularity of screening, may account for the ranging reports of the prevalence and incidence of delirium in this population. Alternatively, wide-ranging prevalence rates may reflect the fluctuating nature of delirium in palliative care inpatients. Globally, with this disorder is reportedly present for 13.3-42.3% patients at admission, 26-62% during their admission, 58.8% in the weeks prior to their death, and for almost all patients (88%) within six hours of death (Hosie et al., 2013).

While the DePAC project did not examine associations between the presence of delirium and patient characteristics, exposures or outcomes, delirium risk factors and outcomes for hospitalised patients are well identified in the literature (Refer Appendix 1.1). Evidence from other populations suggests that it is the characteristics of older age, cancer, pre-existing cognitive impairment and advanced illness that place palliative care patients at a high risk of delirium. These patients' risk increases when precipitants such as infection or dehydration, and iatrogenic precipitants such as psychotropic medication (opioids, benzodiazepines, corticosteroids and antipsychotics), occur (Agar et al., 2015; Caraceni, 2013; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010; Uchida et al., 2015). The presence of delirium subsequently leads to higher risk of poorer outcomes, including increased

suffering, cognitive and functional decline and mortality (Brajtman, 2003; Breitbart, Gibson, & Tremblay, 2002; Lawlor et al., 2000).

The systematic review found that hypoactive delirium was the most prevalent delirium sub-type, occurring in 68-86% of delirious palliative care inpatients (Hosie et al., 2013). This finding is consistent with other studies that also reported the hypoactive subtype to be the most common in delirious older patients with cancer (58%) (Uchida et al., 2015) and palliative care inpatients (35%) (Meagher et al., 2012). The lower proportion of patients experiencing hypoactive delirium reported in Meagher et al's study may reflect that study's different subtype categorisation according to motor behaviour, which resulted in two other subtypes reported: namely, 'no sub-type' and 'varied' (2012), which used an expanded subtype categorisation to that which is currently adopted by the APA-DSM 5 (American Psychiatric Association, 2013). The differing approaches and delirium prevalence data demonstrate how understanding of this complex, multi-faceted disorder is continuously evolving. Also, they illustrate the challenges in determining consistent and effective measurement and recognition strategies in palliative care patients, considering hypoactive delirium is the most frequently occurring subtype and the most challenging to detect (Hosie et al., 2013; Spiller & Keen, 2006).

The moderate to high prevalence and incidence of delirium in this inpatient population merits its consideration as a research, systems and practice development priority (Lawlor et al., 2014).

### 8.2.2 Question 2: Is delirium recognition and assessment guidance available to nurses working in palliative care inpatient settings?

The research reported in this thesis suggests delirium recognition and assessment guidance is not readily available to nurses working in palliative care inpatient settings. The environmental scan revealed that, despite a plethora of delirium knowledge tools (clinical guidelines, screening, assessment and confirmation tools, and patient and family information resources (Australian Commission on Safety and Quality in Health Care, 2013)) being available, these had not been well integrated in the systems of three leading metropolitan palliative care units in Sydney, Australia. Moreover, almost all existing delirium guidelines either explicitly exclude palliative care populations and evidence, or omit recommendations related to delirium at the end-of-life. These omissions occur despite all 'non-palliative care' guidelines explicitly

acknowledging the relationship between delirium and mortality (Australian Commission on Safety and Quality in Health Care, 2014; Barr et al., 2013; Care of the Confused Hospitalised Older Persons Study, 2010; Clinical Epidemiology and Health Service Evaluation Unit Melbourne Health, 2006; Michaud et al., 2007; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010; Royal College of Physicians and British Geriatrics Society, 2006). Excluding and/or omitting palliative care populations and evidence from these clinical guidelines artificially separates the population from the potential benefits of wider delirium initiatives. This anomaly in part may explain why existing delirium knowledge tools are not effectively integrated into palliative care inpatient units.

The nurses who contributed to the DePAC project confirmed the absence of guidance and professed their need of delirium point-of-care screening, assessment and intervention guidance (Hosie, Agar, Lobb, Davidson, & Phillips, 2014; Hosie, Lobb, Agar, Davidson, & Phillips, 2014). Unfortunately, while the recently released Australian Commission on Quality and Safety of Healthcare delirium clinical care standard (2015) specifies the need for routine screening and comprehensive assessment of patients with cognitive impairment, it proposes to exclude patients receiving palliative care; seemingly because of the conventional, rather than evidence-based, understanding that palliative care patients have specialised needs in relation to delirium care (Australian Commission on Quality and Safety of Healthcare, 2015). If this exclusion is accepted, it will reaffirm the status quo that has relegated specialist palliative care inpatient units as exempt from higher-level organisational delirium care directives. Addressing this incongruent separation of palliative care patients from the wider hospital population will do much to strengthen the top-down approach that is both required and requested by the clinicians and managers who participated in the DePAC project.

### 8.2.3 Question 3: What are specialist palliative care nurses' experiences, perceptions and capabilities in delirium recognition and assessment?

On one level, palliative care nurses are acutely aware of patients' delirium symptoms, causing them to feel concern and compassion during and after an episode (Hosie, Agar, et al., 2014). However, nurses struggle to integrate their observations into a coherent delirium diagnostic or definitional framework. Instead, they feel surprised, puzzled and frustrated when trying to make sense of the diverse range of patients'

fluctuating neurocognitive symptoms, and described feeling overburdened with the responsibility of caring for severely agitated and/or very withdrawn patients. Nurses have difficulty precisely naming delirium, perhaps due to the tendency within palliative care to refer to delirium by a range of other less precise and clinically ambivalent terms, such as 'terminal agitation' or 'terminal restlessness'. Use of these imprecise terms implies inevitability of delirium at the end of life, which in turn contributes to inadequate nursing and medical follow up and assessment of delirious patients (Hosie, Agar, et al., 2014). Specialist palliative care nurses' common failure to promptly conduct and communicate a comprehensive assessment to the team after observing delirium symptoms in their patients is likely a contributing factor in the sub-optimal management of this acute disorder in the specialist palliative care inpatient setting (Hosie, Agar, et al., 2014; Hosie et al., 2015).

Delirium tools are widely recommended for improved recognition and assessment by clinicians (Table 3.2). Palliative care inpatient nurses reported the Nu-DESC to be an easy and brief tool that raised their awareness of delirium. However, they questioned the applicability of the Nu-DESC to palliative care inpatients, particularly for dying or drowsy patients. They were also uncertain how to respond when a patient had a positive delirium screen. This doctoral research further revealed that a small number of more experienced palliative care nurses may believe their advanced clinical skills negate their individual need for a tool such as the Nu-DESC to recognise when patients are delirious (Hosie et al., 2015). Yet self-appraisals of this kind are unlikely to reflect actual delirium screening capabilities, as unstructured patient observations are known to be an unreliable means to recognition (Gesin et al., 2012; Mistarz, Eliott, Whitfield, & Ernest, 2011). When faced with a patient experiencing delirium symptoms, nurses conducted varying levels of comprehensiveness of assessment - usually incomplete - which resulted in delays in the needs of patients being addressed (Hosie, Agar, et al., 2014). Moreover, failing to understand and adhere to recommended delirium practice reduces more senior nurses' effectiveness as clinical leaders, whose roles demand they model exemplary behaviour to less experienced nurses. Collectively, these observations affirm the need for inpatient palliative care services to adopt more structured processes of screening and assessment to build nurses' delirium-related capabilities.

The palliative care nurses interviewed in this research appreciated respectful communication and being listened to when they reported changes to patients' awareness, thinking, behaviour or function. Yet they also reported that respectful listening does not always occur within their teams (Hosie, Agar, et al., 2014). Despite a wish for better communication, it was revealed that nurses did not themselves take the lead and initiate conversations with physicians about the Nu-DESC scores of patients, highlighting the need to build palliative care nurses' communication skills and clinical leadership capabilities in delirium care (Hosie et al., 2015). Delirium knowledge tools will be important vehicles for improved interdisciplinary communication, including promoting the use of a common language, and will provide an opportunity for nurses to more effectively co-manage delirium as care partners with their medical colleagues.

### 8.2.4 Question 4: What are the barriers and enablers to nurses recognising and assessing delirium in the palliative care inpatient setting?

Numerous barriers and enablers were identified as operating at the patient and family, clinician, system and evidence levels, as described below and summarised in Table 8.1.

*Patient and family*

Palliative care patients and family are not fully engaged in delirium recognition and assessment processes, despite the distress they experience during and after an episode and their input being integral to optimising care outcomes (Australian Commission on Safety and Quality in Health Care, 2011; Day & Higgins, 2015; O' Malley, Leonard, Meagher, & O' Keeffe, 2008). Team discussions about patients occur away from the bedside and family and often on a weekly, rather than daily, basis. Written information is not provided to patients or families, despite appropriate delirium brochures being readily available within the Australian health care system (Australian Health Ministers' Advisory Council, 2010; Care of the Confused Hospitalised Older Persons Study, 2010)

Commonly used cognitive assessment tools which require patients to answer a series of questions, such as the MMSE (Folstein, Folstein, & Mc Hugh, 1975), are burdensome for many palliative care patients, which may explain in part why clinicians use the few relevant tools available within palliative care units sporadically rather than routinely (Hosie, Lobb, et al., 2014). Many nurses who participated in the

***Table 8.1 Barriers and enablers to nurses' delirium recognition and assessment in palliative care inpatient settings***

| Level | Barriers | Current Enablers | Potential Enablers |
|---|---|---|---|
| Patient and family | Delirium is challenging to recognise<br>Commonly used cognitive assessment tools are burdensome for patients<br>Few delirium tools validated in the palliative care inpatient setting<br>Patients and families are not routinely engaged | Establishment of rapport and trust with the patient<br>Seeking family knowledge of the patient | Routinely engage patients and family in delirium recognition and assessment e.g. provide them with verbal and written information<br>Develop brief, low burden tools and those incorporating family knowledge of the patient, and test their psychometric properties in the palliative care setting |
| Clinician | Time and workload pressures<br>Multidisciplinary rather than interdisciplinary approach:<br>• Disconnected communication, practice and learning<br>Team meetings are infrequent and away from the bedside<br>Lack of respect for nurses' observations<br>• Undefined role and absent nursing leadership<br>Gaps in knowledge, erroneous beliefs, imprecise communication and terminology, over-confidence of some nurses in their recognition capabilities<br>Few delirium education opportunities relevant to palliative care | Generalised awareness of the problem of delirium<br>Compassion and concern for patients<br>Conducting assessment during delivery of care | Build on compassion, concern and awareness of the problem of delirium to:<br>Adopt an interdisciplinary approach:<br>• Connect communication, practice and education<br>Daily interdisciplinary delirium discussion at the bedside<br>Strengthen nurses' communication skills<br>• Clearly define nurses' role and build leadership capacity<br>• Promote respect and value each disciplines' role in delirium care<br>Provide education resources using palliative care scenarios, deliverable locally and widely<br>Encourage nurse involvement in delirium practice change |
| System | Palliative care populations and end-of-life care recommendations are missing from almost all evidence-based delirium guidelines<br>Minimal integration of delirium tools and point-of-care guidance | One evidence-based clinical practice guideline for delirium care of older adults at the end of life<br>Hospital-wide delirium policy and guidelines, where present | Inclusion of palliative care populations and end-of-life care recommendations in all delirium guidelines<br>Hospital wide guidelines, organisational direction and clinical care standards |

DePAC project affirmed delirium is difficult to recognise in certain groups, namely patients with a prior cognitive impairment, whose primary language is not English and/or who are verbally unresponsive (Fick, Hodo, Lawrence, & Inouye, 2007; Hosie et al., 2015; Hosie, Lobb, et al., 2014). Uncertainty regarding the most effective methods and tools to identify delirium for palliative care patients is a barrier to nurses' recognition capabilities (Hosie et al., 2013). While a multitude of delirium tools has evolved over time (Appendix 1.3), these tools have been primarily designed for and tested within settings and patient populations outside of specialist palliative care (Adamis, Sharma, Whelan, & MacDonald, 2010; Wong, Holroyd-Leduc, Simel, & Straus, 2010).

Countering the absence of routine methods for delirium screening and assessment is that nurses' compassionate listening to patients' experiences and distress, and their realisations of mortality and vulnerability, enable better recognition and understanding of the impact of life limiting illness upon the person. Nurses perceive that patients will confide their symptoms and experiences if rapport and trust are established during conversation and physical care. Getting to know the patient as a person also means that nurses better able to recognise when changes signifying delirium occur (Hosie, Lobb, et al., 2014; Mc Carthy, 2003). Actively seeking the insights of family members by phoning them or talking with them when they visit is reported by nurses to be an effective way to gain relevant knowledge about patients' baseline and disturbances to their function, cognition and perception (Hosie, Agar, et al., 2014). While these communication abilities are not alone sufficient to optimally recognise delirium, they are highly valued by patients and family (Brajtman, 2003; Greaves, Vojkovic, Nikoletti, White, & Yuen, 2008; Morita et al., 2007; Namba et al., 2007) and an integral component of comprehensive patient assessment (Nursing and Midwifery Board of Australia, 2006). Combining these nursing attributes with more structured and comprehensive assessments of patients' fluctuating symptoms using appropriate tools would ensure more timely and accurate recognition of patient's delirium and expedite opportunities to address underlying precipitants.

*Clinician*

A key knowledge barrier to delirium recognition is that palliative care nurses do not refer to or apply diagnostic criteria to frame the delirium symptoms they observe in their patients. As in acute and sub-acute hospital settings, time and workload

pressures are present in palliative care inpatient units. Consequently, nurses assess their patients while they are delivering 'hands on' care, such as during showering and providing assistance with meals (Hosie, Lobb, et al., 2014). Brief, observational delirium tools that can be seamlessly woven into elemental patient care are therefore most likely to be feasible for nurses in busy inpatient environments (Hosie, Lobb, et al., 2014). The Nu-DESC fits these criteria, and palliative care nurses who participated in the DePAC project considered it quick and simple to use. However, the Nu-DESC, along with other tools, require further validation in this setting to ensure they are indeed fit for purpose in identifying delirium in this patient population.

The multidisciplinary, rather than an interdisciplinary, team approach is a major barrier to timely and effective delirium screening, assessment and team communication in inpatient palliative care (Nancarrow et al., 2013). A multidisciplinary approach, combined with delirium being historically classified as a psychiatric syndrome and thereby the responsibility of psychiatry, explains why there is no clearly defined delirium role for palliative care nurses and the absence of inter-professional delirium education (Hosie & Phillips, 2014; Sockalingam et al., 2014). Compounding this problem are nurses' perceptions at times of a lack of respect when they reported patients' delirium symptoms, which no doubt has some truth given nurses' self-acknowledged need for better understanding of delirium and unstructured approaches to communicating assessment of delirious patients (Hosie, Agar, et al., 2014). Specialist palliative care nurses are operating within hospital and unit level systems that do not support them as routinely capable in delirium recognition and assessment (Hosie, Agar, et al., 2014; Hosie, Lobb, et al., 2014). Interdisciplinary delirium team care is required to dismantle the current siloing of delirium and cognition screening and assessment according to the discrete purposes of different disciplines (Nancarrow et al., 2013; Newhouse & Spring, 2010).

These knowledge barriers highlight that an additional potential enabler of delirium recognition by nurses is training in use of tools that confirm delirium and of diagnostic criteria being made more readily available to them (Hosie & Phillips, 2014). Most of the nurses participating in the DePAC project acknowledge they have unmet delirium knowledge needs and reported they had not been able to locate delirium learning opportunities relevant to palliative care. They prefer delirium

education that includes patient scenarios and could be delivered locally or within their workplaces (Hosie, Agar, et al., 2014; Hosie, Lobb, et al., 2014).

*Systems*

Minimal integration of delirium tools or point-of-care guidance and absence of hospital wide guidelines and organisational direction are major system level barriers. There is only one evidence-based delirium guideline for older people at the end-of-life (Canadian Coalition for Seniors' Mental Health, 2010) and none which incorporate evidence-based recommendations for the Australian palliative care inpatient population. Despite the prevalence of delirium in inpatient palliative care population, this project has identified that the necessary systems to support recognition and assessment of delirium in the participating Australian units were largely absent or at best disconnected in all three metropolitan services examined. Where there is some semblance of a system, screening and assessment of delirium is sporadically applied. Only two palliative care nurse participants throughout the overall DePAC project reported their service had a hospital policy relevant to delirium care, and each expressed this supported their nursing practice and education of other nurses (Hosie, Lobb, et al., 2014). Otherwise, the DePAC project found an absence of proactive delirium recognition and assessment strategies at the organisational level.

Figure 8.1 (below) provides a summary of the overall findings of the DePAC project at the epidemiological, systems and nursing practice levels.

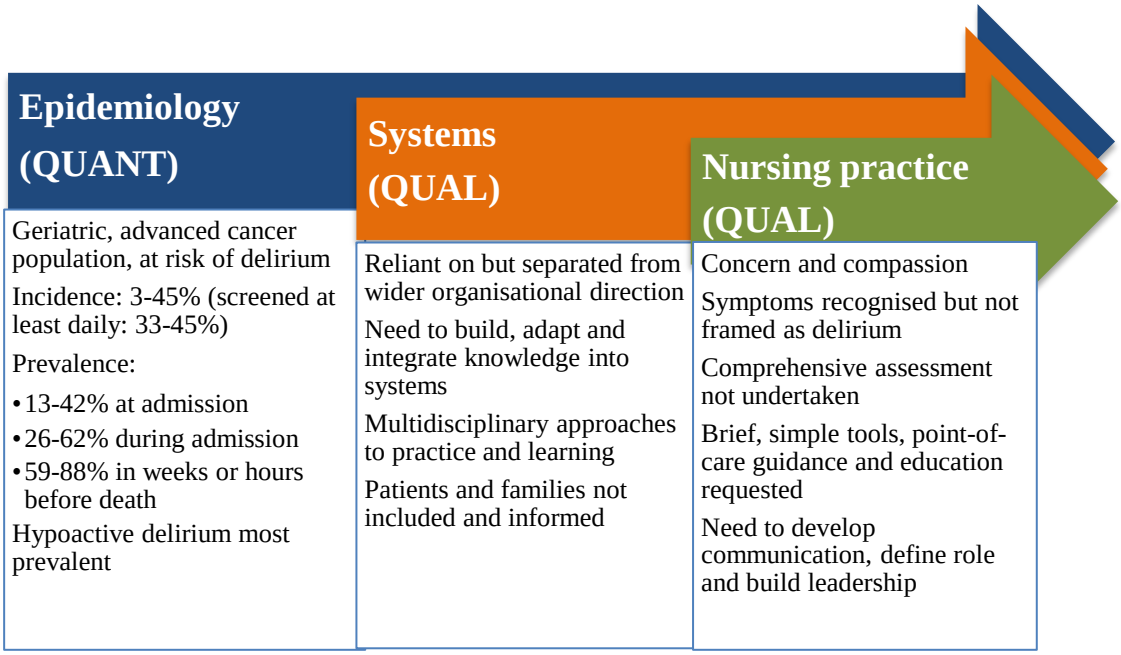


***Figure 8.1 Summary of the overall findings of the DePAC project***

## 8.3 Theorising delirium under-recognition and assessment in specialist palliative care

The final stage of data integration within this mixed methods project was to undertake a meta-inference of the DePAC data. Meta-inference was achieved through applying the complementarity model of triangulation (Erzberger & Kelle, 2003). This level of integration was instrumental in developing theoretical understanding of why the problem of delirium under-recognition and assessment for palliative care inpatients occurs (Cameron, 2009).

As previously described, the DePAC project began with the inference that delirium knowledge is required within systems and practices of the palliative care inpatient unit to improve nurses' recognition and assessment of this acute disorder. This initial understanding is 'Proposition 1' (Figure 8.2). Yet there was uncertainty about the epidemiology of delirium in this patient population and specific actions required to build the capabilities of palliative care nurses in this aspect of care. Quantitative data confirmed the epidemiology of delirium in palliative care inpatients (Hosie et al., 2013; Spiller & Keen, 2006) and the need for knowledge to inform delirium recognition and assessment action within the palliative care inpatient unit. Qualitative data revealed that palliative care evidence, populations and/or recommendations are missing from key knowledge tools such delirium clinical practice guidelines and

screening tools, even though these are largely designed for whole hospital, geriatric or intensive care inpatient populations where a greater number of patients are cared for at the end of their life than within specialist palliative care units (Currow, Burns, & Abernethy, 2008; To, Greene, Agar, & Currow, 2011). Meanwhile, delirium systems, practice and language within palliative care inpatient units are absent, fragmented and/or or non-specific.

Quantitative and qualitative data confirmed Proposition 1 and also generated Proposition 2. The theoretical proposition generated through DePAC data integration is that an artificial separation of patients receiving palliative care from the generation, synthesis and application of delirium knowledge divorces delirium and end-of-life care. This 'divorce' contributes to knowledge to action gaps in end-of-life care for delirious patients within specialist palliative care units, which conceivably might also extend to other care settings. Despite delirium being associated with older age, advanced or serious illness, cognitive impairment, mortality and thereby increasing in frequency as death nears (Hosie et al., 2013; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010; Salluh et al., 2015), delirium is primarily conceptualised within the wider research literature and knowledge synthesis tools as, as Rockwood and Lindesay so eloquently stated: *"…the villain to be vanquished…*," without due heed to the needs of people for whom delirium is *"…heralding the final act in the play of death…"* (2002, p. 236). Palliative care, which seeks to acknowledge death openly as a natural part of life (World Health Organisation, 2002), too heavily weights delirium as an inevitable 'herald' for patients rather than the preventable or reversible 'villain' it may often be (Lawlor et al., 2014). Palliative care nurses have predominantly adopted the overarching conception of delirium being a terminal event for patients who are receiving care in specialist palliative care inpatient units, which is reflected in a distinctive but imprecise diagnostic language that prefixes 'terminal' onto agitated symptoms of delirium (or of other causes), signaling it as a final common pathway. (Heyse-Moore, 2003). This incomplete and erroneous conceptualisation furthermore inadvertently reinforces palliative cares nurses' focus on hyperactive symptoms as opposed to hypoactive delirium, the most common delirium sub-type (Hosie et al., 2013). When inpatient palliative care nurses observe symptoms of delirium it seems they believe their primary role is to move rapidly from recognition of the patients' distress to palliate or 'cloak' this observed

distress as opposed to fully understanding patients' total needs by determining whether delirium is the potentially modifiable source before intervening (Hosie, Agar, et al., 2014). Of special concern are some nurses' views that delirium symptoms arising from iatrogenic causes are innocuous and/or inevitable and simply to be palliated (Hosie et al., 2015). The unintended consequence of administering medication to relieve patients' distress is that it is likely to worsen the severity of patients' delirium symptoms (Agar et al., 2015; Clark & Currow, 2015; Lonergan, Luxenberg, & Areosa Sastre, 2009). Schismatic conceptualisation of the meaning of delirium according to setting or medical specialty means optimal delirium recognition, assessment and responses for patients who are nearing the end of life in any hospital setting are yet to be fully researched, explicated and translated into clinical practice, and this is reflected within specialist palliative care nursing practice.

Figure 8.2 is an adaptation of Erzberger and Kelle's (2003) diagrammatic representation of 'complementarity of results' (Erzberger & Kelle, 2003), and presents the relationships between the theoretical and empirical understandings of the DePAC project. The lines represent the linkages between these understandings, where solid lines represent correspondence of relationship and the broken lines dissonance. The dissonance revealed by the DePAC project occurs between delirium epidemiology in palliative care inpatient populations and response at the research, organisational system and clinical practice levels.

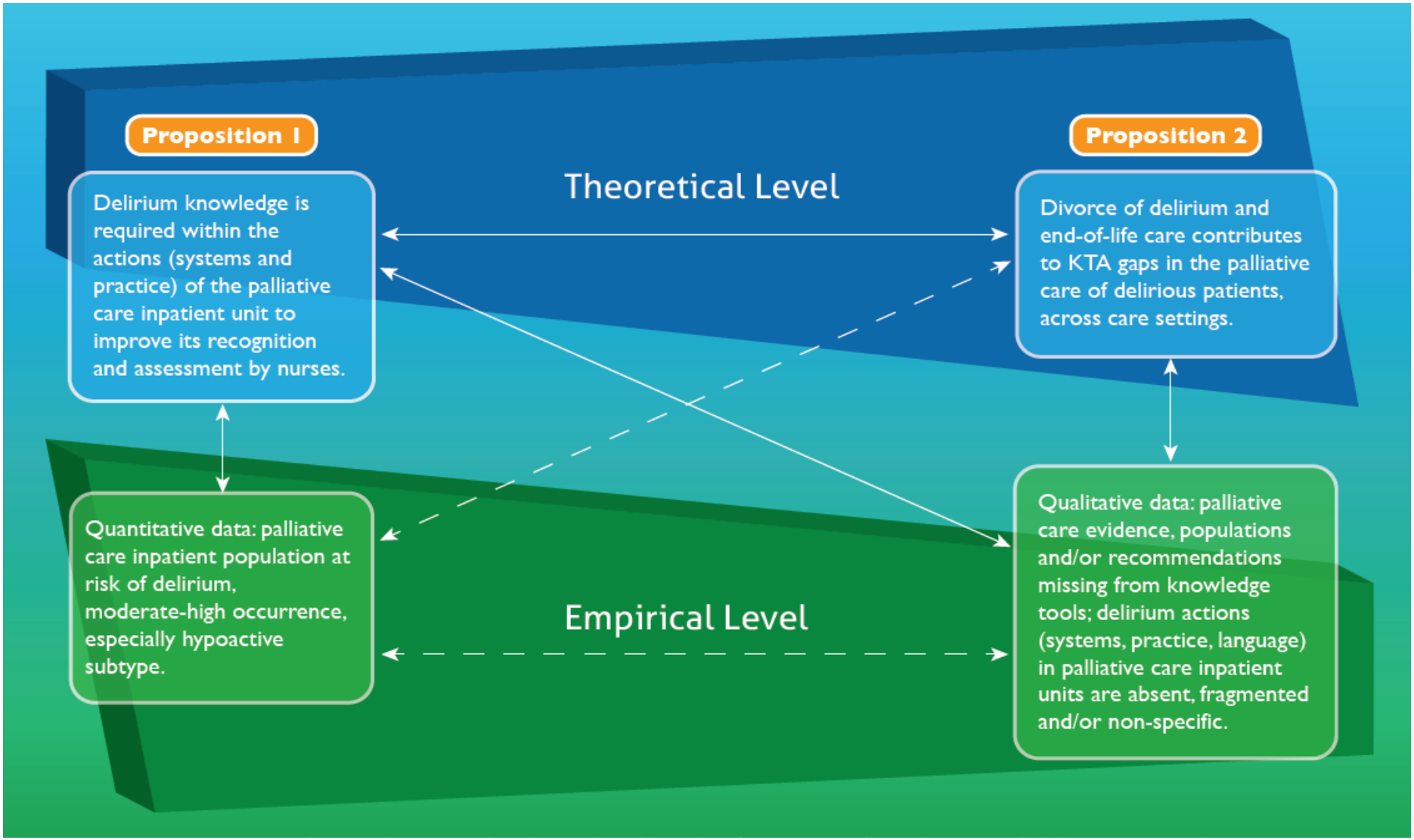


***Figure 8.2 Triangulating theoretical and empirical levels of reasoning for sub-optimal delirium recognition and assessment in palliative care***

## 8.4 Question 5: What is required to improve the capabilities of nurses to recognise and assess delirium in palliative care inpatient settings?

As highlighted above, the DePAC project has identified that improving the capabilities of nurses to recognise and assess delirium in palliative care inpatient settings requires action at the patient and family, clinician and system levels. Leading on from the above summation and meta-inference of the DePAC project data, the required actions for addressing the identified dissonance between delirium epidemiology and organisational and clinician responses, and improving delirium recognition and assessment by nurses, are described below.

Compassionate engagement with people and concern for their distress is central to the spirit of palliative care. Yet effective delirium recognition and assessment in the inpatient palliative unit urgently requires that nurses' attentive listening, compassion and concern for patients and families be transformed into more intentional, structured, informed and routine processes (Hosie, Agar, et al., 2014). This conversion will require nurses to develop greater knowledge of delirium, the tools used to ascertain its presence, master the many elements of comprehensive assessment of a delirious patient, and how to communicate more precisely about delirium with patients, families and their team members. Nurses working in other care settings who have developed the necessary knowledge and skills to accurately screen and confirm when a patient is delirious exemplify the potential for palliative care nurses to achieve such capability, and positively impact patient outcomes related to delirium (Adams et al., 2015; Waszynski, Levick, Andrews, Stowe, & Reagan, 2014).

Yet strategies to improve the capabilities of specialist palliative care nurses to recognise and assess delirium must be targeted more widely than nursing practice alone. As in other settings, a re-configuration of palliative care teamwork into an interdisciplinary model will support effective and sustained change in delirium practice (Brummel et al., 2013; Goldberg et al., 2013). Furthermore, re-conceptualisation of delirium at the end of life to better align with the evidence-base and principles of palliative and person-centred care is required within the minds of palliative care nurses, clinicians, managers, delirium researchers and health care policy makers alike.

The forthcoming delirium clinical care standard contains key components of optimal delirium care, and is vitally important to ensuring better quality and safety of care of patients admitted to sub-acute and acute facilities with palliative care needs (Australian Commission on Quality and Safety of Healthcare, 2015). More than half of all Australians die in acute hospitals (Australian Institute of Health and Welfare, 2014). Some of these patients will be cared for within designated specialist palliative care units, but many more will be cared for elsewhere in the hospital setting (Currow et al., 2008). Delirium does not discriminate according to hospital setting: all inpatients who are frail, elderly, with advanced disease and/or pre-existing cognitive impairment are at risk during a hospital stay (Ahmed, Leurent, & Sampson, 2014; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010). For palliative care patients to obtain the best delirium care wherever they are situated within the hospital setting, the sector must advocate for an inclusive approach to the adoption of this proposed delirium clinical care standard (Australian Commission on Quality and Safety of Healthcare, 2015). For if palliative care units adapt their systems of care to meet the required elements of this standard they will effectively address many of the delirium evidence-based gaps identified by the DePAC project.

There are a multitude of delirium tools available to support timely recognition and confirmation of delirium, and several are brief, observational and/or inclusive of the observations of family, such as the: Nu-DESC (Gaudreau, Gagnon, Harel, Tremblay, & Roy, 2005), 4AT (McLullich, 2014), SQiD (Sands, Dantoc, Hartshorn, Ryan, & Lujic, 2010), RADAR (Voyer et al., 2015) and brief or family versions of the CAM (Ely et al., 2001; Han et al., 2013; Hospital Elder Life Program, 2015; Marcantonio et al., 2014). Measuring and monitoring delirium in Australian palliative care inpatient units would also be strengthened if validated delirium tools were included within the Palliative Care Outcomes Collaborative (PCOC) suite of symptoms and problem screening tools (2014). This widely adopted system for daily screening and data collection of patients' symptoms informs clinical interventions, benchmarking of service provision and quality improvement within individual palliative care services. The epidemiology of delirium within palliative care inpatient units clearly warrants the adaption of this system to include a delirium measure, which will first require confirmation of validity within this patient population (Hosie et al., 2013; Hosie et al., 2015).

The first randomised double-blind controlled trial (RCT) of antipsychotics for delirium management in palliative care recently reported negative results, meaning there are no pharmacological interventions for delirium known to be effective or safe for use in this inpatient population (Agar et al., 2015). This realisation, combined with the knowledge that many medications used to manage common symptoms in advanced disease (i.e. benzodiazepines, opioids, antipsychotics and corticosteroids) can precipitate a delirium (Caraceni, 2013), urges the need for patients and families to be fully advised of the risks of psychoactive medications and their informed consent obtained before they are administered. Many patients value being cognitively alert at the end of life, and some may prefer to forgo a degree of pain relief, for example, to remain more alert, able to engage with others around them and achieve completion of their life's tasks (Steinhauser et al., 2000). Comprehensive assessment of patients' individual needs, including for medication, therefore ought replace the common practice of routine prescription of 'as required' benzodiazepines and other psychoactive medications for patients receiving care within palliative care inpatient units (Clark & Currow, 2015). This practice increases the likelihood that nurses will too hastily and inappropriately choose a medication solution for palliative care patients' distress and agitation, particularly during the night when they may be making decisions for patients without directly consulting their medical colleagues or the patient's family (Hosie et al., 2015).

The absence of effective and safe pharmacological interventions for delirium prevention and management in palliative care patients is a much-needed spur to develop the evidence for non-pharmacological interventions. Interdisciplinary interventions for delirium incorporate core components of nursing care, including: screening, assessment and maintenance of patients' hydration, nutrition, mobility, sleep, vision and hearing, and are effective in reducing delirium incidence, severity, duration and/or impact in other inpatient populations (Adams et al., 2015; Hshieh et al., 2015; Milisen, Lemiengre, Braes, & Foreman, 2005; Naughton et al., 2005). The one delirium prevention intervention conducted in an advanced cancer population incorporated few nursing components, which may explain its ineffectiveness in reducing delirium incidence or severity (Gagnon, Allard, Gagnon, Merette, & Tardif, 2012). This highlights the need for palliative care nurses to bring nursing expertise to the table and actively lead and contribute to future interdisciplinary delirium

interventions. Clinical and research interventions for delirium ought focus on promoting optimal cognitive and physical function of patients receiving care in palliative care inpatient settings as far as is possible. Building the delirium in palliative care evidence will be supported through collaborative research endeavours with other specialities and exemplar initiatives in other care settings. Research collaborations and advocacy will also support the inclusion of palliative care evidence and recommendations within future delirium guidelines.

The following recommendations of the DePAC project relate to the re-modelling of delirium care in palliative care into *interdisciplinary action* directly targeting patient, family and clinician interactions at the unit-level. Recommendations also guide the direction of future *knowledge creation,* incorporating enquiry, synthesis, dissemination, and the tailoring and implementation of delirium tools for the palliative care inpatient setting. The DePAC project thereby informs future clinical practice, policy, advocacy and research aiming to improve delirium outcomes for palliative care patients.

## 8.5 Recommendations of the DePAC project

1. That specialist inpatient palliative care units promote optimal cognitive and physical function for all patients.
2. That palliative care patients and their family be routinely informed about delirium and supported during and after an episode.
3. That all Australian specialist inpatient palliative care teams use delirium diagnostic criteria and validated delirium tools to confirm and communicate observations of patients' neurocognitive changes.
4. That the PCOC tools be expanded to include validated delirium measures.
5. That the assessment of delirious palliative care patients is routine, comprehensive, structured and person-centred.
6. That palliative care inpatient services adopt systems to ensure that the informed consent of patients or their family is obtained prior to nurse administration of psychoactive medication.
7. That the Nu-DESC, 4AT, SQiD, RADAR, and brief and/or family versions of the CAM be validated for use in inpatient palliative care populations.

8. That a suite of palliative care interdisciplinary delirium education resources be developed.
9. That interdisciplinary clinical interventions to improve delirium outcomes for palliative care patients and families be developed and tested.
10. That all future Australian delirium clinical practice guidelines and standards address the needs of palliative care populations in accordance with the best evidence.

## 8.6 Significance of the DePAC project

The DePAC project has contributed to greater awareness and clarity of understanding of delirium occurrence for people receiving care in palliative care inpatients units worldwide and more locally in Australia. Better understanding of the epidemiology of delirium in palliative care inpatients units has informed the need to develop corresponding systems and practice within this setting (Bonita, Beaglehole, & Kjellstrom, 2006). The DePAC project has revealed the actions needed to translate existing delirium evidence into clinical practice and systems, and the steps nurses can take towards realising their full potential within the interdisciplinary team and actively work towards improving delirium outcomes for patients and their families.

The DePAC project was timely as data and insights obtained through this research, along with the afore-mentioned RCT (Agar et al., 2015), have recently informed the first joint submission to government by The Australian & New Zealand Society of Palliative Medicine (ANZPM) and Palliative Care Nurses Australia (PCNA). These two peak palliative care medical and nursing organisations prepared the joint submission to the Australian Commission on Quality and Safety of Healthcare's National Consultation on the draft Delirium Clinical Care Standard (2015) to advocate for the inclusion of palliative care patients within its remit (Appendix 6). This joint submission represents how interdisciplinary collaboration between physicians and nurses may advance the development of delirium care for patients receiving care in Australian specialist palliative care units.

## 8.7 Limitations of the DePAC project

Limitations of each of the studies undertaken within the DePAC project have been described within the relevant Chapters. The limitations of the DePAC project as a whole primarily relate to the limited evidence of the mechanisms by which

knowledge translation research ultimately results in system and practice change (Larocca, Yost, Dobbins, Ciliska, & Butt, 2012; Yost et al., 2015). This limitation signifies the need to not only identify and implement evidence-based approaches to delirium within clinical practice, but also for future translational research undertakings to use evidence-based approaches to system and practice change. Another limitation is that the DePAC project findings may not be transferable to other settings of care, including palliative care inpatient units that are situated within other cultures, health care systems or geographical locations.

## 8.8 Conclusion

An episode of delirium for a palliative care patient potentiates their debilitation, deterioration and suffering, including the pain of disconnection from others. Delirium under-recognition and assessment by palliative care nurses is wholly incongruent with its epidemiology in patients with advanced disease and the goals of palliative care. The fact that palliative care nurses frequently recognise symptoms but fail to recognise that these may constitute delirium, clearly communicate their observations to others in the team, or complete a comprehensive assessment prior to attempting to relieve patients' distress, is reflective of gaps within knowledge, teamwork, organisational and policy approaches to delirium at the end of life. Building the capacity of palliative care nurses to provide exemplary delirium care, including "timely identification and impeccable assessment" (World Health Organisation, 2002) is urgently required, and can be achieved through transforming the multi-level recommendations of the DePAC project into concrete action.

For palliative care patients and those who love them, each day is precious. More careful navigation of patients away from an incipient or existing episode of delirium in the last months, weeks or days of their life is entirely possible and must be considered core business within specialist palliative care inpatient units. We are clearly charged to enable patients receiving care in this setting to remain, as far as is possible, capable of engaging with those whom they love, so that they might fully experience the loving, healing and farewelling that is the real work of this time.

## 8.9 References

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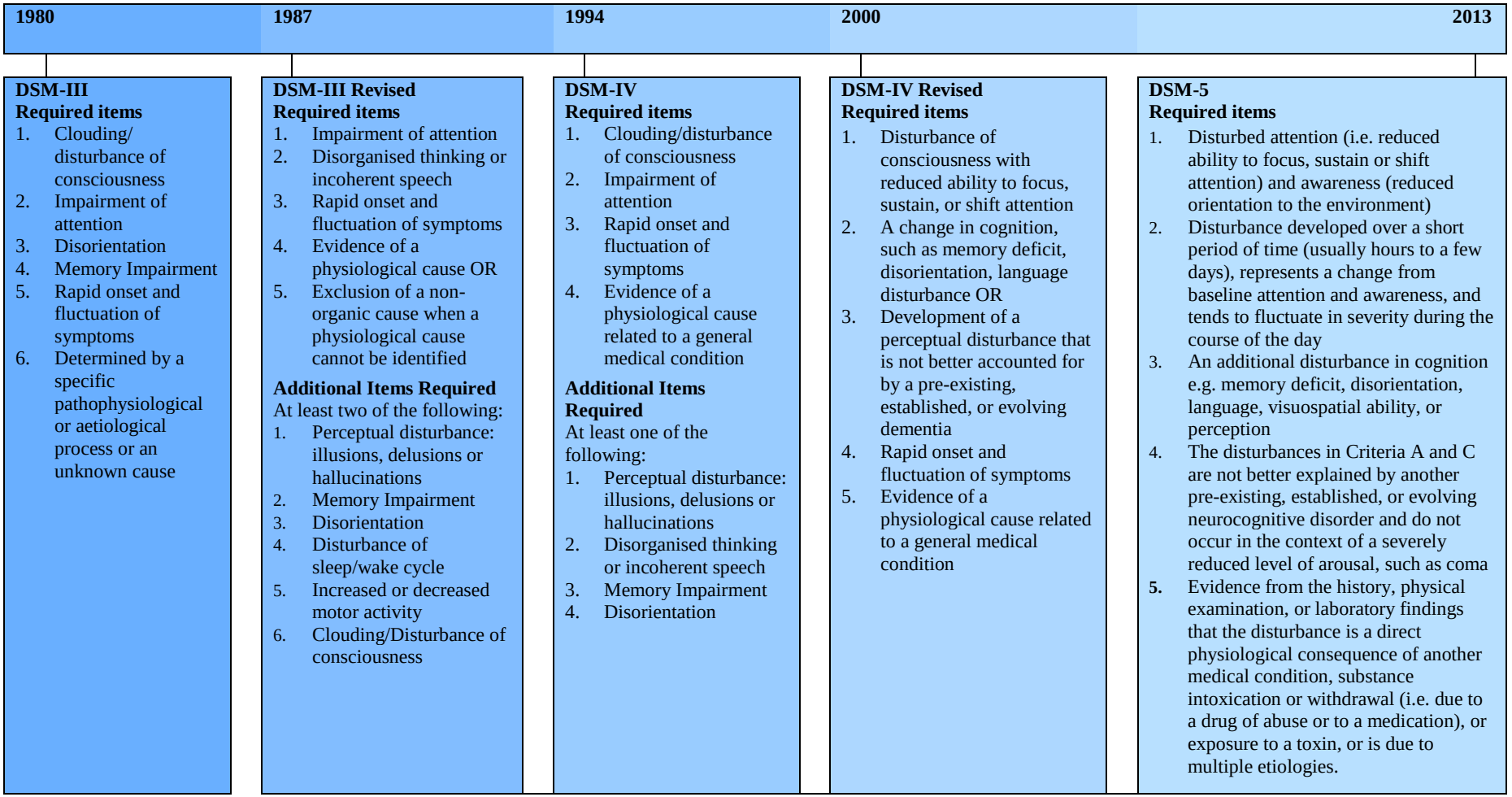
# APPENDIX 1

# *SUPPORTING DELIRIUM INFORMATION*

***Appendix 1. 1 Delirium risk factors***

| **Predisposing factors** | **Precipitating factors** | **Additional risk factors in patients with cancer** |
|---|---|---|
| ≥65 years | Polypharmacy | Prior delirium |
| Advanced illness | Metabolic disturbance | Benzodiazepines |
| Prior cognitive impairment | Low albumin | Opioids |
| Multiple co-morbidities | Prolonged hospital stay | Corticosteroids |
| Sensory impairment | Indwelling catheter | Bone metastases |
| Diminished function/performance status | Drug intoxication | Liver metastases |
| Current hip fracture | Dehydration | Haematological malignancies |
| Impaired nutrition | Infection | Metastases to brain or meninges |
| | Hypoxia | |
| | Pain | |
| | Anemia | |
| | Emotional stress | |
| | Environment | |
| | Use of physical restraints | |
| | Drug or alcohol withdrawal | |
| ***References**: (Ahmed, Leurent, & Sampson, 2014; Canadian Coalition for Seniors' Mental Health, 2010; Caraceni, 2013; Clinical Epidemiology and Health Service Evaluation Unit Melbourne Health, 2006; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010).* | | |

***Appendix 1. 2 Timeline of the evolving APA-DSM diagnostic criteria for delirium 1980 - 2013***



***Appendix 1. 3 Delirium and cognition tools***

| Tool | Relationship with DSM-5 criteria (A-E) | Features |
|---|---|---|
| DRAT (NSW Agency for Clinical Innovation, 2014) | NA | **Delirium risk assessment tool** with three parts: i) Five 'pre-morbid' risk factors: ≥70 years, plus at least one other factor: visual impairment, severe illness, cognitive impairment (according to ATMS <7/10 or MMSE <25/30 or past history of memory or cognitive deficit), or dehydration; ii) Five precipitating factors: mechanical restraint, malnutrition, 3 new medications added in 24 hours, indwelling catheter and iatrogenic event (procedure, infection, complication, fall, etc); iii) If change in behaviour, recommended investigations: CAM, medical review, history including from family, physical examination, medication review, blood and mid stream urine test. |
| 4AT (McLullich, 2014) | A, B, C | 4-item **screening tool for cognitive impairment and/or delirium**. Allows for assessment with drowsy or agitated patients. Includes brief cognitive test items i.e. Months Backwards Test and the Abbreviated Mental Test - 4. Brief (<2 minutes); minimal training required. |
| FAM-CAM (Inouye; Steis et al., 2012) | A, B, C | 11-item **family interview delirium screening tool**. Asks family about changes in recent days to the patient's thinking, concentration and level of alertness, the time of onset, and degree of fluctuation and severity of the changes. Training required, manual available. |
| RADAR (Voyer et al., 2011) | A, C | Originally a 12-item **nurse rated delirium screening tool**, based on observation of the patient's behaviour during each medication administration, a briefer version (3-items, of seven seconds completion duration) has now been validated (Voyer et al., 2015). |
| SQiD (Sands, Dantoc, | B (recent onset), C ('confusion') | **Delirium screening question** to friend or relative: "'Do you think [name of patient] has been more confused lately?' Very brief, no specific training required. Validated as question asked on admission to hospital. |

| Tool | Relationship with DSM-5 criteria (A-E) | Features |
|---|---|---|
| Hartshorn, Ryan, & Lujic, 2010) | | |
| Nu-DESC (Gaudreau, Gagnon, Harel, Tremblay, & Roy, 2005) | A (awareness), C | 5-item **nurse rated delirium screening tool**, administered at end of each 8-hour shift. Scores of $\geq$ 2 out of 10 considered a positive screen. Observational measures: disorientation, inappropriate behaviour, inappropriate communication, illusions/hallucinations and psychomotor retardation. Brief (<1 minute). Usage guidance available within tool. |
| RUDAS (Storey, Rowland, Basic, Conforti, & Dickson, 2004) | C | 6-item **tool to detect dementia in multicultural populations**. Gives a score out of 30, with a cut-point of 23. Measures memory, praxis, language, judgment, drawing and body orientation. Takes approximately 10 minutes. Around 40 minutes training required and training resources available (Alzheimer's Australia). |
| DOSS (Schuurmans, Shortridge-Baggett, & Duursma, 2003) | A, C | 13-item **nurse rated delirium screening tool**, administered each 8/24 shift for a maximum score of 13, based on observations of the patient's behaviour. Over all score is the mean score of three shift scores, with a score of 3 or more indicative of delirium (Detroyer et al., 2014). |
| CAM-ICU (Ely et al., 2001) | A, B, C | 4-item **delirium screening/ascertainment tool**, with a dichotomous end-point (+ve or –ve for delirium) designed for use with patients in Intensive Care Units. Measures features of: acute change or fluctuating mental status, inattention, altered level of consciousness and disorganised thinking. Assessment of each item is guided by structured questions/process. Non-verbal patients can answer through nodding, blinking and/or hand squeezing. Usually takes less than one minute to conduct. Training required; training manual available (Ely, 2014). |
| DRS-R-98 (Trzepacz, | A, B, C, E | 16-item **delirium severity and diagnostic scale**, gives a score of up to 46. Scores of $\geq$ 15 indicate delirium diagnosis. |

| Tool | Relationship with DSM-5 criteria (A-E) | Features |
|---|---|---|
| 2001) | | Severity items: sleep-wake cycle disturbance; perceptual disturbances and hallucinations; delusions; lability of affect; language; thought process abnormalities; motor agitation; motor retardation; orientation; attention; short-term memory; long-term memory; visuospatial ability. Diagnostic items: temporal onset of symptoms; fluctuation of symptom severity; physical disorder. Information gathered from all sources, including physical examination, history gathering and formal cognitive testing. Takes around 15 minutes to complete. Requires clinician training in assessment of "psychiatric phenomenology in medically ill patients"; guidance for use is contained within tool. |
| ICDSC (Bergeron, Dubois, Dumont, Dial, & Skrobic, 2001) | A, B, C | 8-item **delirium screening** tool, validated for use in the ICU, combining a focused assessment (Q1-4), observations over entire shift (Q5-6) and preceding 24-hours (Q7-8). Score: 0 (no), 1 (yes) for each item; scores of 1-3 = subsyndromal delirium, 4-8 = delirium. Items include altered level of consciousness, inattention, disorientation, hallucination, delusion, or psychosis, psychomotor agitation or retardation, psychomotor agitation or retardation, sleep-wake cycle disturbance, symptom fluctuation. Described as 'brief'. Guidance for use available within tool. |
| MDAS (Breitbart et al., 1997) | A, C | 10-item **delirium severity assessment tool** designed to be consistent with the DSM-IV criteria for delirium. Severity of each item scored 0-3; overall score 0-30. Items include: reduced level of consciousness (awareness); disorientation; short-term memory impairment; impaired digit span; reduced ability to maintain and shift attention; disorganised thinking; perceptual disturbance (misperceptions, illusions, hallucinations); delusions; decreased or increased psychomotor activity; sleep-wake cycle disturbance. Later tested in a palliative care population as a diagnostic tool (scores of $\geq$7) (Lawlor et al., 2000). Takes about 10-15 minutes to complete. |

| Tool | Relationship with DSM-5 criteria (A-E) | Features |
|---|---|---|
| CTD<br>(Hart et al., 1996) | A, C | 9-item **cognitive test for delirium**, gives a score out of 30. Measures orientation to time and place, attention, recent memory, comprehension and vigilance. Developed for ICU patient population and uses non-verbal modes of communication (visual, auditory, pointing, head nodding or shaking). Takes around 10-15 minutes to complete. Later abbreviated to a 2-item **cognitive screening test for delirium**: attention and recognition memory, which takes 2-3 minutes to complete (Hart, Best, Sessler, & Levenson, 1997). |
| DSI<br>(Albert et al., 1992) | A, B, C | **Delirium symptom interview** for use by non-clinicians. 65 questions and 45 observations measuring seven items according to DSM-III: disorientation, disturbance of consciousness, disruption of the sleep-wake cycle, perceptual disturbance, incoherence of speech, change in psychomotor activity, fluctuating behavior. Takes around 15 minutes (plus time to complete score), longer if the patient is delirious. Training required; training manual available. |
| CAM<br>(Inouye et al., 1990) | A, B, C | 4-item **delirium screening/ascertainment tool** with a dichotomous end-point (+ve or –ve for delirium). Full version requires assessment of 9 items: acute change in mental status from baseline, inattention, disorganised thinking, altered level of consciousness, disorientation, memory impairment, perceptual disturbances, psychomotor agitation or retardation. A positive CAM requires: 1. Acute onset and fluctuating course AND 2. Inattention AND *either* 3. Disorganised thinking *or* 4. Altered level of consciousness. Takes about 10 minutes to complete. Short version (4-items, observational) available. Moderate level of training needed; training manual available (Inouye, 2003). |
| CDT<br>(Sunderland et al., 1989) | A | A **cognitive screening tool** and also used to **measure decline during dementia**. The patient is asked to draw a clock face with a specified time e.g. 10 minutes past 11. Brief, takes about two minutes (plus time to complete score). Several scoring methods are available. |

| Tool | Relationship with DSM-5 criteria (A-E) | Features |
|---|---|---|
| BOMC (Katzman, Brown, & Fuld, 1983) | A, C | 6-item **measure of dementia or cognitive impairment**. Somewhat complex weighted scoring system based on errors, overall score of 0-28, with scores ≥ 10 indicating cognitive impairment. Measures orientation (year, month, time of day), memory (recall of a given name and address) and concentration (numbers 20-1 and months of year from December backwards). Described as 'brief. Minimal training required, scoring guidance available with tool. |
| MMSE (Folstein, Folstein, & Mc Hugh, 1975) | A, C | 11-question **cognition assessment tool**, gives a score out of 30. Measures orientation to time and place, recent memory and attention, ability to name, and follow commands. Verbal and manual tasks. Takes approximately 8 minutes; minimal training required. |
| AMT (Hodkinson, 1972) | C | 10-item **cognitive assessment tool.** Items: memory; orientation. Scores < 7 or 8 suggests cognitive impairment. Takes five minutes to complete. Minimal training required. |

Code: **AMT** Abbreviated Mental Test **BOMC** Blessed Orientation-Memory-Concentration **CAM** Confusion Assessment Method **CAM-ICU** Confusion Assessment Method for the Intensive Care Unit **CDT** Clock Drawing Test **CTD** Cognitive Test for Delirium **DOSS** Delirium Observation Screening Scale **DRAT** Delirium Risk Assessment Tool **DRS-R-98** Delirium Rating Scale-Revised-98 **DSI** Delirium Symptom Interview **FAM-CAM** Family Confusion Assessment Method **ICDSC** Intensive Care Delirium Screening Checklist **Nu-DESC** Nursing Delirium Screening Scale **RADAR** Recognising Active Delirium As part of your Routine **RUDAS** Rowland Universal Dementia Assessment Scale; **MDAS** Memorial Delirium Assessment Scale **MMSE** Mini-Mental State Examination **SQiD** Single Question in Delirium

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# APPENDIX 2

# *PUBLICATIONS*

Review Article

PALLIATIVE MEDICINE

Palliative Medicine
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# Delirium prevalence, incidence, and implications for screening in specialist palliative care inpatient settings: A systematic review

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**Abstract**

**Background:** Delirium is a serious neuropsychiatric syndrome frequently experienced by palliative care inpatients. This syndrome is under-recognized by clinicians. While screening increases recognition, it is not a routine practice.

**Aim and design:** This systematic review aims to examine methods, quality, and results of delirium prevalence and incidence studies in palliative care inpatient populations and discuss implications for delirium screening.

**Data sources:** A systematic search of the literature identified prospective studies reporting on delirium prevalence and/or incidence in inpatient palliative care adult populations from 1980 to 2012. Papers not in English or those reporting the occurrence of symptoms not specifically identified as delirium were excluded.

**Results:** Of the eight included studies, the majority (98.9%) involved participants (1079) with advanced cancer. Eight different screening and assessment tools were used. Delirium incidence ranged from 3% to 45%, while delirium prevalence varied, with a range of: 13.3%–42.3% at admission, 26%–62% during admission, and increasing to 58.8%–88% in the weeks or hours preceding death. Studies that used the *Diagnostic and Statistical Manual–Fourth Edition* reported higher prevalence (42%–88%) and incidence (40.2%–45%), while incidence rates were higher in studies that screened participants at least daily (32.8%–45%). Hypoactive delirium was the most prevalent delirium subtype (68%–86% of cases).

**Conclusion:** The prevalence and incidence of delirium in palliative care inpatient settings supports the need for screening. However, there is limited consensus on assessment measures or knowledge of implications of delirium screening for inpatients and families. Further research is required to develop standardized methods of delirium screening, assessment, and management that are acceptable to inpatients and families.

**Keywords**

Cancer, delirium, incidence, inpatients, palliative care, prevalence, review, screening

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## Introduction

Delirium is a serious neuropsychiatric syndrome in hospitalized patients, including those within palliative care settings,[1–3] and is associated with increased mortality.[4,5] Delirium impacts upon the patient's ability to communicate, their decision-making capacity, functional ability, and quality of life.[1] Patients who recover from an episode of delirium usually recall the experience[6,7] and report feeling frightened and humiliated.[8] In the last days or hours of life, hyperactive delirium symptoms—commonly referred to as "terminal agitation" or "terminal restlessness"—cause distress for family members.[9–11]

Core symptoms for a *Diagnostic and Statistical Manual* (*DSM*), *Fourth Edition* (*DSM-IV*) diagnosis of delirium include disturbed consciousness, with reduced ability to focus, sustain, or shift attention; altered cognition or a perceptual disturbance, acute onset and fluctuating symptoms, which can be mild and fleeting or severe and persistent; and evidence of an etiological cause.[12] Level of consciousness identifies the three delirium subtypes: hyperactive, hypoactive, or mixed.[13] Lethargy, mood changes, and altered sleep–wake cycle can also occur, although are not required to establish a diagnosis.[12]

Despite numerous interventions for delirium reversal, management and support of palliative care patients with delirium being available, evidence of their effectiveness is evolving and requires further development.[14–16] Identifying delirium is an important priority as approximately half of all delirium episodes are potentially reversible.[4,17] Iatrogenic causes, such as opioids and benzodiazepines, underscore the importance of recognition to modify palliative care interventions.[18,19] Optimal recognition and assessment of delirium is of clinical and ethical concern since sedation is commonly used to manage symptoms of restlessness and agitation in the terminal stage.[20,21] Underrecognition of delirium results in interventions being inconsistently applied in palliative care.[22–24]

Screening improves clinician recognition of delirium,[25] yet is not routinely conducted in the inpatient palliative care setting.[26] Previous reviews of delirium in palliative care settings have provided comprehensive examinations of the literature including delirium prevalence and assessment methods,[1,3,27] but to date, no reviews have examined in detail the methodological quality of delirium epidemiological studies conducted in palliative care inpatient settings, nor discussed implications of results in conjunction with other evidence required to justify implementation of routine delirium screening.[28,29]

## Method

### Aims and review processes

This systematic review aims to: (1) examine prevalence and incidence of delirium and delirium subtypes in specialist palliative care inpatient settings, at various stages of patients' admission, (2) describe how delirium cases were identified and established in included studies, and (3) discuss results in relation to implementation of routine delirium screening in specialist palliative care inpatient units.

Although a meta-analysis of data was not undertaken, the Meta-Analysis of Observational Studies in Epidemiology (MOOSE)[30] guidelines were followed to facilitate systematic processes in the completion and reporting of the review, where relevant.

### Search method

A systematic review was undertaken between 1 December 2011 and 29 February 2012 and was limited to the studies published since 1980, when delirium was first identified within the *DSM, Third Edition* (*DSM-III*),[31] up until early 2012. Prospective search questions guided the search strategy using the following search Medical Subject Headings (MeSH) and key words, along with their associated derivatives: "delirium" OR "confusion" OR "terminal agitation" OR "terminal restlessness" OR "psychomotor agitation" OR "cognitive failure" OR "disorientation" AND "palliative care" OR "death" OR "dying" OR "terminal care" OR "hospice care" OR "terminally ill" OR "end of life" AND "prevalence" OR "incidence" OR "epidemiology". Search engines used were Scopus, CINAHL, and Medline. In addition, the search terms "delirium" AND "prevalence" OR "incidence" OR "epidemiology" were employed in PubMed using the palliative care filter from CareSearch.[32] Reference lists of included studies and relevant reviews[1,3] were also examined to search for other potentially eligible papers.

### Study selection

Criteria for inclusion of papers were prospective assessment studies reporting prevalence, incidence, or rate of occurrence of delirium, conducted within specialist palliative care inpatient settings (defined as palliative care inpatient units or hospices) with adult participants. Studies were excluded if they were not published in English, or reported the rate of occurrence of symptoms or phenomena that were not specifically categorized as delirium, such as "cognitive failure," "confusion," or "terminal agitation," as the interchangeable use of such terms has previously contributed to a lack of clarity in reporting and collating of delirium occurrence in palliative care populations.[3] Two authors (A.H. and J.P.) examined the titles and abstracts of all papers to determine if they met the inclusion criteria, one author (A.H.) extracted the data from potentially relevant studies ($n = 13$) and this guided decision making (A.H. and J.P.) about inclusion of studies.

### Assessment of methodological quality of included studies

The first author (A.H.) assessed the methodological quality of included studies with reference to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines[33] and criteria developed by Boyle[34] to evaluate prevalence studies, which were reviewed and confirmed by the other author (J.P.) as follows:

1. Sample:
   a. Explanation of how the sample size was determined;
   b. Study population clearly defined;
   c. Two-phase sampling process: delirium screening followed by more comprehensive delirium assessment;
   d. Minimum of 80% participation within eligible study population;
2. Measurement:
   a. Standardized data collection methods for all participants of the study;
   b. Use of valid delirium-screening and assessment tools AND/OR psychiatric assessment;
   c. Reporting of measurement reliability processes, for example, user training in the delirium-screening and assessment tool(s), inter-rater reliability testing, supervision of clinical/research staff conducting study measurements;
3. Analysis:
   a. Confidence intervals included for statistical analysis of frequency estimates.

## Results

The initial search generated 815 papers: Scopus ($n = 758$), CINAHL ($n = 28$), Medline ($n = 8$), PubMed via CareSearch ($n = 21$). Within Scopus, adding "AND prospective study," further refined the search and reduced the number of results within Scopus to 84 papers, resulting in 141 papers across all search engines. Once duplicates were removed, 119 papers published between 1980 and 2011 remained (Figure 1). A further 113 papers were removed as they did not report primary research data and/or prospectively measure prevalence or incidence rates of delirium in adult specialist palliative care inpatient units, leaving six papers. Two additional papers[35,36] were identified from a hand search of the reference lists of the eligible papers and other reviews.[1,3] At the end of the search, eight studies that prospectively measured the prevalence or incidence of delirium in specialist palliative care adult inpatient settings remained (Table 1).[4,5,35–37,39–41] These included studies which were conducted in the northern hemisphere over a 12-year period (1996–2008).

### Setting, diagnosis, and demographics

The included studies were undertaken in patient settings described variously as hospices ($n = 2$),[39,41] palliative care units ($n = 3$),[35–37] acute palliative care units ($n = 2$),[4,40] and a combined acute palliative care unit/hospice ($n = 1$).[5] Where described, the purpose of the settings included symptom control, respite, rehabilitation, and/or terminal care for palliative care patients. The majority (98.9%) of all participants ($n = 1079$) across these studies had advanced cancer, with some diagnoses not specified in one study.[41] Two studies included participants with other life limiting diseases: (a) immunodeficiency disorders ($n = 11$)[36] and (b) end-stage cardiac failure and cerebrovascular disease ($n = 1$).[41]

Across the studies, there was equal representation of males and females, with a mean age of 66.24 years (range 62–68.7 years). Participation rates varied (Table 1).

### Study characteristics, design, quality, and focus

There was variability in study characteristics, design, quality, and foci, as well as participant numbers (X 120, range 41[40]–228 people[5]). No studies reported statistical explanations for determination of sample size, with this appearing to be largely determined by number of patient admissions within study periods. Delirium occurrence was measured at different frequencies and points of time during the admission, while five studies measured both delirium prevalence and incidence.[4,35,36,39,41]

Different criteria were used to define the terminal stage, with the last weeks of life considered the "pre-terminal and terminal" stage of cancer in two studies.[5,39] "Terminally ill" or "terminal" cancer patients were elsewhere considered to be within the last 6 months of life.[37] Only one study included the data specifically collected in the 6 hours immediately prior to death, defined as "terminal delirium."[4]

Methodological quality of studies varied considerably and no study met all quality criteria (Table 1).

### Definitions of delirium and diagnostic criteria used

Diagnostic criteria adopted by many of the studies, conducted at different time points, reflect the evolution of the *DSM* diagnostic criteria for delirium. The majority ($n = 6$) of studies applied *DSM* criteria to diagnose delirium, with two using the research gold standard of psychiatrist assessment to confirm delirium against the *DSM* version current at the time.[5,37] In another four studies, diagnosis of delirium was based on the presence of the then-current *DSM* criteria, although not confirmed by psychiatric assessment.[4,35,39,41] The remaining two studies used an alternative criteria to establish a delirium diagnosis with one[36] using the International Statistical Classification of Diseases and Related Health problems (ICD-10) Diagnostic Criteria for Research,[42] which requires a greater range of symptoms to be present to establish a delirium diagnosis.

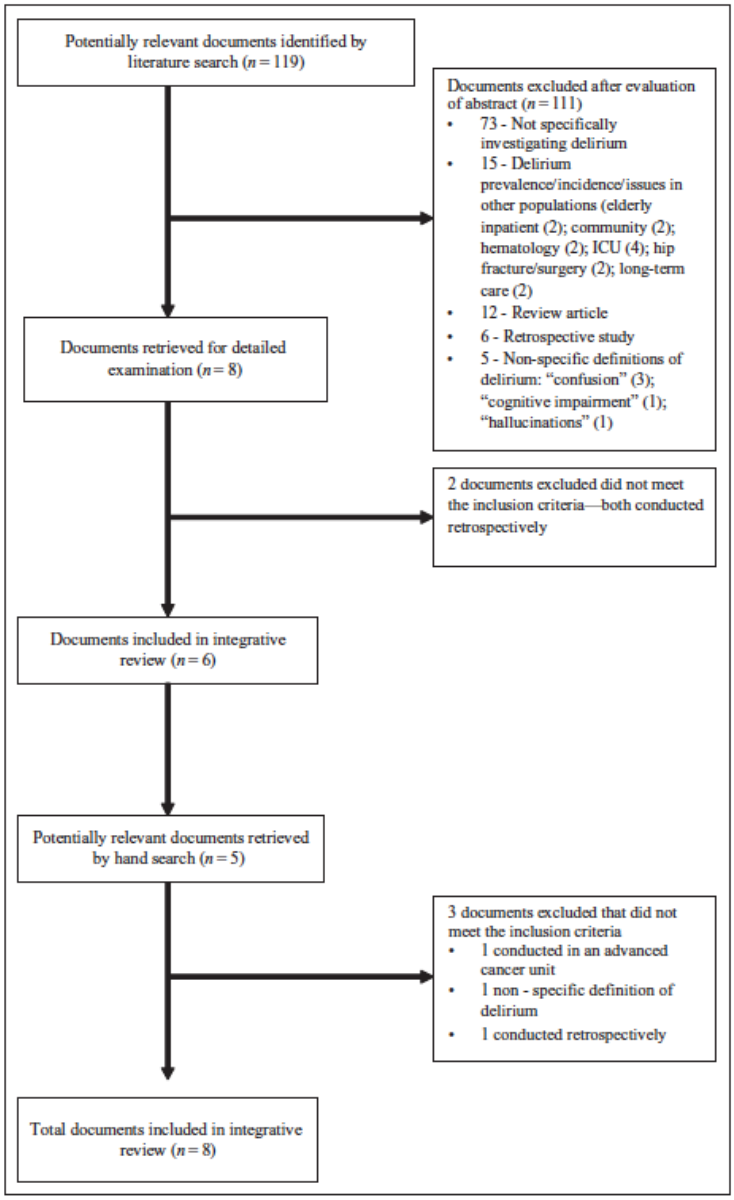


**Figure 1.** Flowchart of studies from search to inclusion.

### *Screening and assessment tools*

Eight different tools were used across the studies to assess cognition, screen for, or establish delirium (Table 1). Of the six delirium-specific screening or assessment tools, all varied in their validity, purpose (screening, diagnosis, and severity), intended rater (psychiatrically vs nonpsychiatrically trained), ratings procedures (observation vs interview), number of items, and extent to which they correlate with different versions of *DSM* criteria for delirium.[43,44]

Three delirium or "confusion" screening tools included the Confusion Rating Scale (CRS) used by ward nurses[39,45];

**Table 1.** Summary of included studies.

| Publication | Country | Focus | Design/screening and assessment tools/*DSM* Criteria | Participants/ participation rate | Delirium prevalence/ incidence results | Quality considerations |
|---|---|---|---|---|---|---|
| Minagawa et al.[37] | Japan | To demonstrate a range of psychiatric disorders in a PC unit. | Prospective assessment by psychiatric investigator using MMSE, psychiatric assessment, and SCID within 1 week of admission.<br>*DSM-III-R* | Terminally ill cancer inpatients ($n$ = 93); 59% male; mean age 67.2, SD ±11.9 years; participation rate 85% | 53.7% met *DSM-III-R* criteria for a psychiatric disorder<br>*Prevalence*: 28% ($n$ = 26).<br>Delirium most common psychiatric disorder | Sample size: inpatients recruited over a 13-month period.<br>MMSE assesses cognitive function, but is not specific to delirium. SCID does not evaluate organic mental disorders—however, delirium diagnosis determined by psychiatric assessment<br>Confidence intervals not included |
| Lawlor et al.[4] | USA | To evaluate the occurrence, precipitating factors, and reversibility of delirium in an acute PC unit | Prospective serial assessment in a consecutive cohort. DOCS (by trained ward nurses each 8-h shift), MMSE (by medical investigators on admission and twice weekly), MDAS (by medical investigators for delirious patients).<br>Semi-structured interview by medical investigators to operationalize *DSM-IV*. | Advanced cancer patients ($n$ = 104 of 113); 51% male; mean age 62 years, SD ± 1.9 years; participation rate 100% | *Prevalence on admission*: 42% ($n$ = 44)<br>*Incidence*: 45% of patients who were delirium-free on admission ($n$ = 27/60)<br>*Prevalence hours before death*: 88% ($n$ = 46/52) | Sample size: inpatients recruited over a 9.5-month period<br>DOCS had no reliability or validity testing<br>MMSE assesses cognitive function, but is not specific to delirium<br>Researcher training and moderate-to-high inter-rater reliability in MDAS use was reported in a separate paper[38] |
| Gagnon et al.[39] | Canada | To determine delirium frequency and outcome in hospice inpatients | Prospective cohort study. CRS (by trained ward nurses 8th-hourly), BOMC to assess orientation, CAM (by two research nurses to diagnose delirium). Training and supervision of research nurses by psychiatric investigator<br>*DSM-III-R* | Terminal cancer inpatients ($n$ = 89) with a life expectancy <2 months; 48% male; mean (median) age 66 years (68 years); participation rate 95% | *Prevalence*: On admission, 20.2% patients ($n$ = 18) had delirium symptoms, diagnosis confirmed in 133%<br>*Incidence*: 52.1% of 71 patients delirium-free at admission developed delirium symptoms, diagnosis confirmed in 32.8% | Sample size: inpatients recruited over a 4-month period<br>CRS requires further validation |

*(Continued)*

**Table 1.** (Continued)

| Publication | Country | Focus | Design/screening and assessment tools/*DSM* Criteria | Participants/ participation rate | Delirium prevalence/ incidence results | Quality considerations |
|---|---|---|---|---|---|---|
| Sarhill et al.[40] | USA | (a) Evaluate the use of the BCS and (b) determine prevalence, cause, precipitants, and treatment of delirium in an acute PC medicine unit | Prospective assessment by medical officer on admission using the BCS (delirium = score of ≥2)<br>*DSM* criteria for delirium not used | Consecutive patients with advanced cancer ($n$ = 41/50); 44% male; median age 65 years; participation rate 82% | *Prevalence*: 31.7% ($n$ = 13) on admission | Sample size: inpatients recruited over a 2-month period<br>Multiphase sampling not used—delirium screening only<br>BCS requires further psychometric testing<br>Not specified who applied BCS (medical clinician, researcher, or investigator)<br>Confidence intervals not included. |
| Durkin et al.[41] | UK | To clinically assess the prevalence of psychiatric disorder occurring in a PC unit and ascertain whether disorder had been detected and treated prior to admission | Prospective assessment of patients on admission and twice weekly by principal psychiatric investigator. Presence or absence of a psychiatric diagnosis was determined according to the ICD-10 Diagnostic Criteria for Research | Inpatients with diagnosis of AIDS or advanced cancer ($n$ = 224); 52% male; mean age 66 years, $SD$±14.2, range 22–90 years; participation rate 100% | 62% ($n$ = 139) met ICD-10 diagnostic criteria for psychiatric disorder<br>*Prevalence*: 19% ($n$ = 43)<br>*Incidence*: 3% patients ($n$ = 5/181) delirium-free on admission developed delirium | Sample size: inpatients recruited over a 6-month period<br>Multiphase sampling did not occur—no delirium-screening tool used<br>Confidence intervals not included |
| Lam et al.[42] | Hong Kong | To estimate the incidence and prevalence of delirium in a PC unit and evaluate psychomotor type, etiologies, reversibility and other characteristics | Prospective daily assessment of consecutive admissions using structured evaluation, MMSE—Cantonese version, KPS. Patients assessed as delirious had further assessment by medical investigator within the same day to confirm delirium diagnosis. Experienced and trained nurse administered MDAS within 24 h of delirium diagnosis<br>*DSM-IV* | Advanced cancer patients ($n$ = 82/102); 46% male; mean age 68 years, $SD$±12.5; participation rate 80%. | *Prevalence*: 58.8% ($n$ = 30/51) of patients who died had delirium on average 12.4 days before death<br>*Incidence*: 40.2% ($n$ = 33)<br>*Subtypes*: 70% hypoactive<br>*Severity*: 53.3% mild severity, 23.3% moderate, 20% severe | Sample size: inpatients recruited over a 4-month period<br>MMSE assesses cognitive function, but is not specific to delirium<br>Training and supervision of clinical staff conducting daily delirium monitoring was not reported |

Table 1. (Continued)

| Publication | Country | Focus | Design/screening and assessment tools/*DSM* Criteria | Participants/ participation rate | Delirium prevalence/ incidence results | Quality considerations |
|---|---|---|---|---|---|---|
| Spiller and Keen[43] | Scotland | To assess the prevalence of hypoactive delirium in specialist PC settings | Study 1: Prospective assessments at admission and 7 days later by study investigator using MMSE, CAM, MDAS, FSS, HADS<br>Study 2: 48-h point prevalence study in 8 specialist PC units using MMSE, CAM, MDAS (administered by trained clinical staff, discipline/s not specified)<br>*DSM-III-R* | Study 1: Hospice inpatients ($n$ = 100); 49% male: mean age 68.7 years, SD ± 15 years; 99/100 advanced malignancy; participation rate 88% at admission, 73% at 7 days<br>Study 2: Inpatients ($n$ = 109) of 8 PC units (6 hospices, 1 hospice ward within a general hospital, 1 PC service within a general hospital); gender not specified; mean age 68.7 years, diagnoses not specified; participation rate 87% | Study 1: *Prevalence:* 29% ($n$ = 29) at admission—86% hypoactive, 14% mixed 26% ($n$ = 19/73) had delirium 7 days later—68% hypoactive, 21% hyperactive, 11% mixed<br>*Incidence:* 7% ($n$ = 5 /73) within 7 days of admission.<br>Study 2: *Point prevalence:* 29.4% ($n$ = 32) (range 14%–35%). 78% hypoactive, 6% hyperactive, 16% mixed | Determination of sample size of 100 for Study 1 was not explained. MMSE assesses cognitive function but is not specific to delirium.<br>No reporting of researcher training in use of CAM, MDAS in Study 1<br>Diagnoses of study population not reported in Part 2<br>Confidence intervals included in Part 1, but not Part 2 |
| Fang et al.[44] | Taiwan | To determine the prevalence, detection, and treatment of delirium in an acute PC/ hospice unit | Survey and chart review, screening by trained research nurse using the DRS-CV at admission and second daily, followed by psychiatrist review for +ve DRS-CV to verify diagnosis and determine delirium subtype<br>*DSM-IV* | Terminal cancer inpatients ($n$ = 228/457); 51% male; mean age 64.57 SD ± 14.88; participation rate 49.9% | *Prevalence:* 46.9%.<br>*Subtypes:* 68.2% hypoactive, 21.5% hyperactive, 10.3% mixed | Sample size: inpatients recruited over a 6-month period<br>Largest sample within included studies, but participation rate <80%. 51% of nonparticipants were too ill to consent, indicating selection bias |

BOMC: Blessed Orientation Memory Concentration; BCS: Bedside Confusion Scale; CAM: Confusion Assessment Method; CRS: Confusion Rating Scale; DOCS: Delirium Observational Checklist Scale; DRS-CV: Delirium Rating Scale–Chinese Version; DS: Delirium Scale; *DSM: Diagnostic and Statistical Manual*; *DSM-III-R: DSM, Third Edition, Text Revision*; FSS: Fatigue Severity Scale; HADS: Hospital Anxiety and Depression Scale; KPS: Karnofsky Performance Scale; MDAS: Memorial Delirium Assessment Scale; MMSE Mini-Mental State Examination; PC: palliative care; SCID: Structured Clinical Interview for *DSM-III-R*; ICD-10: International Statistical Classification of Diseases and Related Health problems.

the Bedside Confusion Scale (BCS) used by medical investigators[40,46]; and the Delirium Observational Checklist Scale (DOCS), an instrument developed by study investigators for ward nurse's use.[4] Although the BCS was previously validated in the palliative care setting, it requires further investigation of its psychometric properties.[43] The CRS requires further validation, and the DOCS is not a validated delirium-screening tool.[43]

Two cognition assessment tools, used to either screen for delirium or to assist in delirium assessment, were the Mini-Mental State Examination (MMSE)[47] used by psychiatric and medical investigators[4,35,37,41] or clinical staff[41] and the Blessed Orientation Memory Concentration (BOMC) test used by research nurses.[39,48]

Three delirium assessment tools were the Confusion Assessment Method (CAM)[49] used by research nurses[39] or medical investigators and trained clinical staff[41]; the Memorial Delirium Assessment Scale (MDAS)[38,50] used by medical investigators,[4,41] trained clinical staff,[41] or a research nurse[35]; and the Delirium Rating Scale–Chinese Version (DRS-CV)[51] used by a research nurse.[5] Only the MDAS[38,50] and the Delirium Rating Scale (DRS)[46,52,53] were validated in palliative care or advanced cancer populations prior to use in the studies under examination, with the MDAS undergoing further simultaneous validation.[4,38,41] The CAM[49] was validated in other clinical settings and languages,[43] and subsequently validated in the palliative care setting.[54]

No studies reported perspectives of patients or families of the acceptability of delirium-screening and assessment processes.

### Delirium prevalence and incidence rates

The prevalence and incidence rates reported in the included studies are represented graphically in Figure 2.

*On admission.* Five studies measured delirium prevalence at admission, ranging from 13.3% to 42.3% of patients.[4,36,39–41] Of 104 advanced cancer admissions to an acute palliative care unit, delirium was present at admission in 42.3% of patients.[4] A later study, consecutively measured delirium frequency in hospice inpatients ($n = 89$) and 13.3% were confirmed to have delirium.[39] In another, 19% of patients ($n = 224$) admitted to a palliative care unit had delirium.[36] A third (32%) of participants ($n = 41$) were classified as delirious according to presence of inattention and altered level of alertness in one acute palliative care unit,[40] while 29% of participating patients ($n = 100$) admitted to a Scottish hospice had delirium.[41]

*During admission.* Delirium prevalence across the whole cohort of palliative care inpatients during each study period ranged from 26% to 62%.[5,37,39,41] One study measuring psychiatric morbidity at one point during the week after admission to a palliative care unit found that delirium was the most prevalent psychiatric disorder, occurring in 28% of all participants and representing 52% of all psychiatric diagnoses.[37] Another study, using delirium screening during each 8-h shift, identified that 62% of participants developed delirium at some point during hospice admission.[39] One study reassessed hospice patients ($n = 73$) 7 days after admission and found that 26% had delirium, while across 8 hospices or inpatient palliative care services, 29.4% of patients had a delirium diagnosis during a 48-h period of assessment.[41] Recently, 46.9% of palliative care inpatients ($n = 228$) screened second daily were found to have delirium.[5]

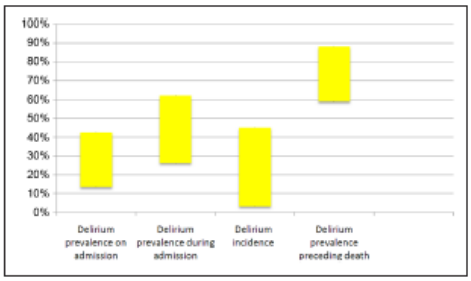


**Figure 2.** Graphical representation of delirium prevalence and incidence rates in specialist palliative care inpatient units from results of included studies.

Three studies examined occurrence of delirium subtypes and all reported that the majority of delirious patients experienced hypoactive delirium (68%–86%).[5,35,41]

Five studies measured delirium incidence after admission and reported rates of between 3% and 45%.[4,35,36,39,41] Delirium developed during admission in 45% of patients ($n = 60$).[4] In a later study involving 71 participants, 32.8% had confirmed delirium.[39] These two studies included screening by ward nurses each 8-h shift.[4,39] A study using daily screening reported, of admitted patients, 40.2% ($n = 82$) developed delirium ($n = 33/82$), the majority (70%) having hypoactive delirium of mild severity (53.3%).[35] In contrast, one study reported development of five new cases in 73 patients within a 7-day period, an incidence of 7%,[41] while another, using twice weekly assessment and the ICD-10 diagnostic criteria, reported an incidence of only 3%: during the 6-month study period only 5 of 181 patients delirium-free on admission subsequently developed delirium.[36]

*Preceding death.* Two studies measured prevalence of delirium in the weeks or hours before death, reporting rates of 58.8%–88%.[4,35] The most recent study reported 58% delirium prevalence in patients ($n = 51$) who died during admission.[35] Only one study explicitly measured and reported occurrence of delirium in the last 6 h of life in an

acute palliative care unit and found that the majority (88%) had delirium.[4]

### Variation in delirium prevalence and incidence according to study methods and settings

Studies that used *DSM-IV* criteria reported higher delirium prevalence (42%–88%)[4,5,35] and incidence (40.2%–45%)[4,35]; compared to studies using earlier versions of *DSM* criteria and ICD-10 (prevalence 13.3%–29.4%[36,37,39,41] and incidence 3%–32.8%).[36,39,41] Studies screening participants daily or more often reported higher delirium incidence (32.8%–45%)[4,35,39] than studies that screened or assessed delirium participants less frequently (3%–7%).[36,41] Delirium prevalence on admission varied slightly across settings: palliative care unit (19%), hospice (13.3%–29%), and acute palliative care units (31.7%–42%).

### Role of clinicians in the identification and diagnosis of delirium

In four studies, clinicians were actively involved in delirium screening and assessment study processes.[4,35,39,41] In two, ward nurses screened for delirium, using the DOCS[4] or the CRS[39] and received training in use of tools and features of delirium.[39] In another, an experienced and trained nurse assessed delirious patients using the MDAS to measure delirium severity.[35] In the study involving 8 separate Scottish hospices and palliative care services, clinicians received training prior to using the CAM and MDAS to identify and assess delirium over a 48-h period.[41]

Research nurses were also involved in delirium screening and assessment. The DRS-CV was used to screen inpatients for delirium,[5] delirium diagnosis was established by nurses in another using the CAM in consultation with the psychiatric investigator if there was uncertainty about the diagnosis,[39] and delirium severity was measured by nurses using the MDAS 24 h after delirium diagnosis by a physician.[35]

## Discussion

There were some similarities across studies, with most adopting a two-phase sampling method—delirium screening followed by assessment—and involving patients of a similar age and primary cancer diagnosis. However, there was a varying methodological quality across these studies, with heterogeneity of diagnostic criteria, sample sizes, frequency of assessment, and measurement tools adopted. Despite these differences and the variation in reported delirium occurrence, categorizing delirium prevalence at different points along the palliative care inpatient trajectory indicates that prevalence is lower at admission (range 13.3%–42.3%),[4,36,39–41] increases during admission (range 26%–62%),[5,37,39,41] with the risk of developing delirium escalating as death nears (range 58.8%–88%).[4,35] This review has confirmed that palliative care inpatient populations have delirium incidence and prevalence equal to or greater than other known high-risk populations, such as older people admitted to hospital,[55] Intensive Care Units,[56–58] post hip surgery,[59,60] and long-term care.[61]

The review adds to the emerging evidence that hypoactive delirium is the most prevalent subtype in palliative care populations.[5,35,41,62] Hypoactive delirium may appear less severe than other subtypes[35] and cause less difficulties in ward management,[63] but is associated with increased mortality.[5] It also has a significant impact on patients and families since cognitive changes occur as often as in the hyperactive and mixed subtypes.[62,64]

Clinicians were involved in patient screening and assessment in half the studies, highlighting potential for routine delirium screening outside a research context, and feasibility of increasing delirium recognition capabilities by nonpsychiatric clinicians through training and access to validated delirium-screening and assessment tools.[38,50,54] Delirium screening by nurses in a hospice setting has been demonstrated to be feasible and effective.[14,25] However, the challenges of screening for delirium in palliative care populations was also demonstrated by the small proportion of included studies measuring delirium occurrence specifically in cohorts of patients who were dying, and proportion of patients and/or families who declined to participate in the delirium assessment process, indicating delirium assessment is not always acceptable to them. Additionally, many patients were too unwell to provide consent or were excluded because they were dying, comatose, or could not speak. Similarly, a recent study[14] reported a low rate of CAM completion by hospice nurses (39%), highlighting the difficulty of conducting this delirium assessment in the last days of life and need for validated low-burden delirium assessment tools at this time.

Applying the *DSM-IV* criteria appears to lead to increased case finding, which has been previously reported[65]; and interestingly, variability in delirium prevalence and incidence noted in this review reflects results of similar reviews that included studies using less-specific delirium definitions.[1,3]

### Implications for clinical practice and future research

As daily screening increases detection of incident delirium,[4,35,39] the question remains: should routine screening be implemented in palliative care inpatient settings? Clinical practice guidelines for other high-risk patient populations recommend screening to improve early recognition of delirium,[55,66,67] although the extent to which this has been routinely adopted is unknown. However, a number of other key questions require investigation to justify routine screening[28,29] including: Is screening acceptable to patients and

family and cause minimal harm? Is it cost-effective? Does early recognition and treatment of delirium improve mortality and morbidity? And, what are the adverse effects of delirium treatment?[28,29]

Further research in delirium prevention interventions in palliative care,[14] and high-level evidence of the efficacy and safety of pharmacological interventions, such as antipsychotics, benzodiazepines, and methylphenidate, is needed.[16,68,69] Measuring impact of interventions on delirium incidence, severity, and patient mortality should continue to be a focus of research, but as improvements in morbidity and mortality are likely to be minimal in this population and the focus of care is a relief of distress and suffering, patients' and families' subjective experiences (such as perceptions of care, distress, dignity, and quality of life) related to delirium screening, recognition, and treatment are especially important outcomes to be determined.[70] Development of acceptable, observational delirium screening and assessment strategies for palliative care patients who are very ill, dying, or unable to communicate is also required.[8,28,29]

This review has highlighted the lack of consensus regarding selection of delirium screening and assessment tools in palliative care research, and this is likely to be reflected in clinical practice. Establishing the acceptability of various delirium-screening and assessment tools by patients and families would inform the sector about which are the most appropriate to use in this population, particularly in the dying stage. Establishing consensus would facilitate delirium benchmarking, quality improvement,[71,72] and consistency of research methodology. To further improve methodological and reporting quality of future delirium epidemiological research in palliative care populations, consideration of recently developed guidelines for observational studies in epidemiology is recommended.[33,73]

Health-economic analysis will also be an important inclusion in future delirium research, when high healthcare costs associated with delirium occurrence in elderly inpatient populations is considered.[74,75]

### *Study limitations and strengths*

Limitations of this review include exclusion of papers not published in English, potentially contributing to selection bias and the absence of multiple independent raters in the extraction of data to assess eligibility and quality of included studies. There are limitations related to generalizability of this review due to the focus on advanced cancer diagnoses within study populations.[70] As the brief of palliative care shifts to nonmalignant conditions and settings where end-of-life care is routinely provided, for example, elderly medical inpatient settings or nursing homes, it is important to consider implications of this changing population.[76–78] In addition, although results suggest increasing delirium prevalence as death nears, this was not confirmed within this review due to variable reporting of participants' functional status and illness staging, and variation in operational definitions of "terminal." This barrier has been previously noted with a recommendation that all future delirium occurrence studies incorporate a patient cohort classification system based on estimated prognosis.[3]

The strengths of this review include use of a systematic approach, with application of accepted guidelines and a structured approach to the assessment of quality of included studies.[30,33]

## Conclusion

This review has examined methods, quality, and results of studies prospectively measuring delirium occurrence in specialist palliative care inpatient settings and identified additional evidence needed to justify routine delirium screening in these settings. While the moderate to high rate of delirium occurrence in palliative care inpatient units supports the need for delirium screening, there is also a need to develop consensus and quality of methods for measuring delirium occurrence, and we require evidence regarding impact, acceptability, potential harms and cost-effectiveness of delirium screening and assessment, and outcomes of screening and treatments on morbidity, mortality, and patients' and families' subjective experiences.

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# Palliative care nurses' recognition and assessment of patients with delirium symptoms: A qualitative study using critical incident technique

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ABSTRACT

*Background:* Delirium is prevalent in palliative care inpatient settings and management is often challenging. Despite nurses' integral patient care role, little is known about palliative care nurses' capacity to recognise, assess and respond to patients' delirium symptoms.
*Objective:* To explore the experiences, views and practices of inpatient palliative care nurses in delirium recognition and assessment.
*Settings and participants:* 30 nurses from nine Australian specialist palliative care inpatient services.
*Design and methods:* Critical incident technique (CIT) guided a series of semi-structured interviews. Prior to interviews participants were given a vignette of a palliative care inpatient with an unrecognised hypoactive delirium, to prompt their recollection and recounting of a similar clinical incident. Clearly recalled and described incidents were analysed using thematic content analysis.
*Findings:* 20 of 30 participants recalled and described 28 relevant delirium incidents. Two themes and six sub-themes provide a general description of participants' experiences, views and practice in delirium recognition and assessment. Participants experience distress related to caring for patients with delirium and express compassion and empathy for delirious patients. Enhancing their delirium knowledge, strengthening collaborative multidisciplinary team relationships and better communication are important supports. Some participants, usually those in advance practice roles, describe more comprehensive assessment capabilities that incorporate clinical expertise with whole person awareness, yet systematic and structured delirium screening and assessment processes and application of the delirium diagnosis criteria are largely missing. Use of ambiguous terminology to describe delirium symptoms contributes to ineffective practice.

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*Conclusions:* The findings of this study expands our understanding of how palliative care nurses' capacity to recognise and assess patients' delirium symptoms in the inpatient setting could be strengthened.



**What is already known about the topic?**

- Delirium is a distressing, prevalent and potentially reversible neuropsychiatric syndrome in palliative care inpatient populations.
- Delirium, particularly the hypoactive subtype, is under-recognised by clinicians.
- Nurses' experience and practices in delirium are shaped by their workplaces and personal values and philosophies, with palliative care nurses' experiences and practices explored in only a small number of studies.

**What this paper adds**

- Palliative care nurses may often recognise patients' delirium symptoms but there is variability in their capacity to comprehensively assess patients, situate the observed neurocognitive changes within a delirium framework and consistently apply accurate delirium terminology.
- Effective delirium practice is supported by fostering of inter-personal relationships and communication with patients, families and medical colleagues, while palliative care nurses' delirium learning often occurs after clinical uncertainty and challenging situations.
- Routine use of delirium risk, screening and assessment tools are missing from practice. Adoption of currently available tools may assist palliative care nurses' shape their thinking about this complex syndrome and enable them to respond to changes in their patient's clinical status in more timely and appropriate ways.

## 1. Background

Delirium is a complex neuropsychiatric syndrome that occurs frequently in palliative care inpatient populations, with delirium prevalence ranging from 13 to 42% on admission, 26 to 62% during admission, and 58 to 88% in the last weeks and hours of life (Hosie et al., 2013). The syndrome manifests as acute and fluctuating changes to patients' awareness, cognition and/or perception (American Psychiatric Association, 2000) causing distress for patients, both at the time of the delirium episode and later, when they recall their delirium experience (Breitbart et al., 2002; OMalley et al., 2008). Patients with delirium exhibit several psychomotor symptoms, broadly classified into three subtypes: (1) hyperactive delirium – increased motor activity, agitation and heightened states of arousal; (2) hypoactive delirium – decreased motor activity, delayed response and drowsiness; and (3) mixed delirium – fluctuation between hyperactive and hypoactive states (De Rooij et al., 2005; Gupta et al., 2008; Meagher, 2009). In palliative care inpatient units, hypoactive delirium is most prevalent, associated with increased mortality and is significantly under-recognised by clinicians (Fang et al., 2008; Lam et al., 2003; Leonard et al., 2008; Spiller and Keen, 2006). Despite its quieter presentation, patients experiencing this sub-type experience as much distress as those with hyperactive or mixed delirium (Breitbart et al., 2002). Delirium also adversely impacts on patients' relationships, function and ability to make decisions (Breitbart et al., 2002; Spiller and Keen, 2006) and leads to increased distress, anxiety and decision making for family members (Brajtman, 2003; Buss et al., 2007; Morita et al., 2007; Namba et al., 2007).

This serious, distressing syndrome has multiple potential causes – some iatrogenic (e.g. opioids, benzodiazepines, steroids and chemotherapeutic medications) (Agar and Lawlor, 2008) – and is potentially reversible (Lawlor et al., 2000; Leonard et al., 2008), making early recognition of delirium symptoms and comprehensive assessment of the patient integral for targeted and optimal treatment and support (Canadian Coalition for Seniors' Mental Health, 2010; Registered Nurses Association of Ontario, 2003, 2004). Delirium treatments and support ought be multi-faceted and individually tailored to: reverse the cause/s (e.g. administering antibiotics for infection or oxygen for hypoxia; withdrawing or ceasing medication precipitants); ensure adequate nutrition, hydration, elimination and comfort and that hearing and vision aids are used; provide reassurance and information to the patient and family; promote a peaceful, safe ward environment; encourage the presence of patient's family; and/or administer psychotropic medications for severe delirium-related distress and agitation (Canadian Coalition for Seniors' Mental Health, 2010; Clinical Epidemiology and Health Service Evaluation Unit, 2006; Palliative Care Expert Group, 2010). If psychotropic medications are required, continued assessment of the patient's response and for presence of adverse effects, including delirium exacerbation, is essential (Canadian Coalition for Seniors' Mental Health, 2010; Meagher et al., 2013; Palliative Care Expert Group, 2010).

### *1.1. Nurses' delirium knowledge, practice and experiences*

Nurses' intimate patient interactions over the 24 h period makes them ideally placed to recognise early delirium symptoms, assess the patient and apply appropriate treatment and supportive interventions. Yet nurses' capacity to effectively care for patients with delirium is limited by their: under-recognition of delirium (Rice et al., 2011; Steis and Fick, 2008; Voyer et al., 2012), knowledge and practice gaps (Fick et al., 2007; Hare et al., 2008a,b) and distress and strain of caring for a patient with delirium (Belanger and Ducharme, 2011; Breitbart et al., 2002;

Leventhal et al., 2013). Workplace culture and settings (Agar et al., 2012; Belanger and Ducharme, 2011) and nurses' personal values and philosophies (Mc Carthy, 2003) also shape their delirium knowledge, views and practices. Nurses who consider ageing as natural and not synonymous with disease are more likely to recognise delirium symptoms as a deviation from normal and consequently assess for potential causes, as do nurses with better knowledge of the patient and/or great role autonomy (Mc Carthy, 2003).

While two studies have explored palliative care nurses' perspectives of caring for patients with 'terminal delirium' (Brajtman and Mc Pherson, 2006) or delirium management generally (Agar et al., 2012), our study has intentionally focused on palliative care nurses' experiences, views and practices of delirium 'recognition' and 'assessment', primarily because these practice elements are pivotal points around which subsequent appropriate clinical decision-making and effective palliative care are implemented (Nursing and Midwifery Board of Australia, 2006; World Health Organisation, 2002).

### 1.2. Aim

To explore the experiences, views and practices of inpatient palliative care nurses in delirium recognition and assessment.

## 2. Design and methods

### 2.1. Critical incident technique

Critical incident technique (CIT) guided semi-structured interviews and data analysis. CIT is a flexible set of principles applied to gather detailed information about how experts in a certain domain approach a procedure or significant situation and meanings they attach to this situation (Flanagan, 1954; Keatinge, 2002; Kemppainen, 2000). Defining features of CIT include: it focuses on determining facts, as opposed to generalisations, to find solutions to practical and real problems; uses either direct observation or obtains participants' clearly described memories of a specific incident; and these incidents, rather than participants, are the units of analysis (Butterfield et al., 2005; Flanagan, 1954; Kemppainen, 2000). CIT identifies effective, ineffective and missing practices (Schluter et al., 2008), is useful for reflecting on professional practice (Hettlage and Steinlin, 2006) and has the advantage of allowing for brief interviews (Kemppainen, 2000). CIT was considered to be a feasible and non-threatening method to achieve this study's aim (Butterfield et al., 2005), while also being a meaningful and powerful way to tap into clinical events that may have a lingering effect on nurses and their practice (Keatinge, 2002).

### 2.2. Development and use of a vignette

Vignettes are brief descriptions of clinical situations, used as an effective and economical means to explore or test clinician knowledge and/or decision-making (Fick et al., 2007; Mc Crow et al., 2013; Veloski et al., 2005). A vignette of a palliative care inpatient with unrecognised hypoactive delirium was developed and provided to participants shortly before their interview (Text Box 1). The vignette aimed to focus participants' attention onto delayed recognition of the symptoms of hypoactive delirium (the least recognised but most prevalent subtype of delirium in palliative care settings) (Fang et al., 2008; Lam et al., 2003; Spiller and Keen, 2006) and prompt their recall of a similar delirium incident from their clinical practice. It was anticipated that the vignette would be clinically relevant, familiar and accessible to all participants, regardless of their depth of delirium knowledge (Agar et al., 2012; Steis and Fick, 2008). After careful consideration, this approach was considered to be more appropriate than merely asking participants to recall and recount 'a patient experiencing delirium'.

Vignette development was informed by the literature (Leonard et al., 2009; Meagher, 2009; Spiller and Keen, 2006). Validity, clarity and feasibility were undertaken by members of the research team [PD, MA, EL, JP], each of whom have clinical and research expertise in nursing, delirium and/or palliative care; and confirmed during pilot interviews with nurses ($n=4$) with different levels of experience, from two palliative care units.

**Box 1.** Vignette

Mrs X is admitted to your palliative care unit on Monday. She is widowed, aged 81, lives alone and her diagnosis is advanced lung cancer. The reason for admission is for symptom management, as she has escalating pain. She has a son and daughter, but she is unaccompanied by any family or friends at admission. Medical and nursing admission processes are completed. Mrs X was independent with ADLs prior to admission. She shares a four-bed room with three other female patients.

Her opioid and adjuvant doses are increased after admission and by day 3 her pain appears to be improving.

Mrs X is a quiet, cooperative lady who displays no signs of agitation, but is noted to be a little vague in her verbal responses. She interacts only occasionally with the other patients in the room. She sleeps for intervals during the day, and is sometimes slow to rouse. Night staff report that she is awake for periods of time each night. When awake, she sits quietly and watches what is happening in the room.

Her son visits her each evening after he finishes work. On the evening of the 4th day of admission, he speaks to the nurse on duty and tells her that his mother has told him that she can see a dead man in the corner of the room, and that it has been there since she arrived on the ward. He also reports that his mother is not as clear in her speech and thinking as is usual for her.

The nurse speaks to Mrs X about this. Mrs X says she has been wondering why no one has talked about this man and that she was too frightened to report what she was seeing, in case people thought she was 'crazy'. She reveals that she finds the sight of the dead man very disturbing, and is worried she is 'losing her marbles'. She also reports she is finding it harder to concentrate and remember simple things.

### 2.3. Participants and settings

Registered or enrolled nurses (New South Wales Government, 2011) working in clinical roles in Australian specialist palliative care inpatient settings, with at least three months experience in this setting and at least 12 months clinical experience overall, were eligible to participate. In Australia, a 'specialist palliative care service' is defined as: "a multi-disciplinary health care service whose substantive work is with patients who have a life limiting illness." (Palliative Care Australia, 2005, p. 7).

### 2.4. Recruitment and informed consent process

Two discrete strategies were used to optimise recruitment and promote inclusion of a heterogeneous sample (Kemppainen, 2000), with invitations distributed via: (1) Specialist palliative care inpatient units; and (2) A nursing social media site (Hosie, 2013). Participants could choose to participate in a telephone or face-to-face interview (Sturges, 2004).

At participating units, nursing managers circulated the participant information and consent form to eligible nurses and notified them of interview times. Nurses who were interested in participating in a face-to-face interview met with the researcher [AH] at these times. Written consent was obtained after eligibility was confirmed, provision of information about the study and its voluntary nature, and questions answered. Nurses who expressed interest via the nursing social media site were emailed the participant information and consent form, and followed up within a week to ascertain their continued interest in participating [AH]. A scripted verbal consent was audiotaped prior to all telephone interviews, with participants forwarding their signed consent post interview.

### 2.5. Ethical approval

University and hospital ethical and governance approvals for this study were obtained prior to recruitment.

### 2.6. Data collection

Face-to-face interviews were conducted within a private room within each unit. The vignette was offered to participants between half to 1 h before interviews, with most electing to read this in the private room just prior to interview commencement. The procedure for telephone interviews varied slightly: the vignette was emailed to participants a couple of hours prior to scheduled interviews, with AH unaware of the exact time of receipt. During telephone interviews, AH was located in a private office and participants in their workplace office or home. Consistent with the CIT, the interview was intentionally designed to be of around 20 min (Kemppainen, 2000). A question route (Text Box 2) was used for all interviews.

Interviews were audiotaped and conducted respectfully and supportively, so that participants felt safe to disclose incidents that were potentially difficult to share, due to the clinical situation or sub-optimal outcomes (Schluter et al., 2008). Participants were reassured that the interview was voluntary and its aim was not to 'test' their knowledge or review their individual performance, but to seek their insights. Interviews proceeded even when participants could not immediately recall a relevant incident, as some participants recalled and recounted an incident during their interview. When incidents were not generating any new behaviours, views, themes or subthemes, indicating data saturation, a further five participants were recruited and interviewed to confirm data saturation (Flanagan, 1954; Kemppainen, 2000; Liamputtong and Ezzy, 2005).

**Box 2.** Interview route

**Introduction to the interview**

"Thank you for agreeing to participate. The interview may take about 20 min. It will be audiotaped and I may also take some notes during the interview. Is that OK with you?

During the interview I will ask you some questions about your experience in nursing a palliative care patient who has acute changes in their awareness, thinking and perception, with the focus on how nurses recognise and assess these changes. The interview is not meant to be a test, we are mainly looking for insights into what nurses think are the most important things to do when caring for patients with these changes. You might find you feel a bit nervous, or as you recall your experiences it is possible this may bring up some feelings for you. It is OK to not answer all of the questions, or to ask for a break if you need it. Have you had a chance to read the case study? Are you ready to start now?"

**Interview questions**

1. Does this case study reflect a situation you have observed or experienced recently in your own clinical practice?
2. Can you tell me about one particular patient situation in detail?
3. How did you feel about the situation?
4. What did you do?
5. In looking back at that situation, is there anything you would do differently?
6. Thinking about the future, do you have any suggestions for what we as nurses could do to better recognise the changes and manage the situation?

**Conclusion of the interview**

"Thank you for your time – I really appreciate your input. Do you have any further comments or questions? Remember, you can contact me by phone or email if you want to discuss the interview or study."

### 2.7. Reflexivity

While not working as a colleague or manager of participants, the interviewer [AH] is an experienced palliative care nurse. This contextual knowledge required maintenance of objectivity, so open-ended

and 'obvious' questions were asked during interviews and participants sometimes prompted to provide greater detail or explanation (Flanagan, 1954; Schluter et al., 2008). For example: "So when you say 'validation' what do you mean exactly by that?" During interviews, participants expressed varying views and practices in delirium recognition and assessment, at times surprising and differing to those of AH, who was immersed in the delirium literature. This required AH to foster a heightened awareness of and appreciation for all participants' views and experiences, re-examine her own standpoint about nursing practice in delirium recognition and assessment, and investigate and reflect more deeply on what the nursing practice currently was, ought be and why nurses' views might differ (Jootun et al., 2009). Reflections were recorded, meditated upon and discussed with doctoral supervisors and fellow researchers.

### 2.8. Analysis

All interviews were transcribed verbatim. Field notes were completed immediately after each interview, noting relevant information not captured on tape, summarising key points and recording initial observations and insights (Schluter et al., 2008). From the interview transcripts, all incidents (the units of analysis) were collated into an electronic spread-sheet. In accordance with CIT only incidents with: (i) an antecedent; (ii) a clear and full description of the incident; and (iii) an outcome, were included for data analysis (Flanagan, 1954). Any recollections that were vague, generalised or lacking in detail – suggesting either inaccurate recall or insufficient knowledge of the event (Flanagan, 1954) or not providing a clear outcome or information about effectiveness of actions (Bradbury-Jones and Tranter, 2008) – were omitted.

CIT has a distinct framework for data analysis that is consistent with other qualitative methodologies (Butterfield et al., 2005), with Flanagan (1954) providing broad recommendations for stages of data analysis: (1) Determining a frame of reference; (2) Formulating categories inductively; and (3) Determining level of specificity (i.e. dozens of specific behaviours) or generality (i.e. a few representative behaviours) to report the data (Butterfield et al., 2005; Flanagan, 1954). In our study, interview questions provided the frame of reference for initial recording of data (incidents) into an electronic spread-sheet [AH]. Data analysis was an inductive process, using thematic content analysis (Bradbury-Jones and Tranter, 2008; Glaser and Strauss, 1968; Schluter et al., 2011) and began during data collection. Transcripts, field notes and spread-sheets were read and re-read, promoting immersion in the data and close examination of individual incidents. Incidents and behaviours were then compared and contrasted: for example, what was occurring in incidents where there was more timely delirium recognition, assessment and intervention, compared to incidents where there was not? Theme and sub-theme development began [AH, JP]. Preliminary categories, themes and sub-themes were discussed with the researcher team [AH, JP, MA, LL, PD]; this analysis helped to refine the key themes and sub-themes to more accurately reflect the data. Congruent with the exploratory aim, these themes and sub-themes represent a more general, rather than specific, description of incidents and participants' perspectives.

**Table 1**
Characteristics of the sample ($n = 30$).

| Characteristic | Number |
|---|---|
| Gender | |
| Female | 29 |
| Male | 1 |
| Age | |
| 21–30 | 3 |
| 31–40 | 11 |
| 41–50 | 9 |
| 51–60 | 6 |
| 61–70 | 1 |
| Position title | |
| Registered Nurse | 16 |
| Clinical Nurse Specialist | 6 |
| Enrolled Nurse | 2 |
| Clinical Nurse Consultant | 2 |
| Nursing Unit Manager | 2 |
| Clinical Nurse Educator | 1 |
| Nurse Practitioner Candidate | 1 |
| Highest qualification | |
| Certificate | 5 |
| Diploma | 4 |
| Bachelor | 9 |
| Post graduate certificate | 9 |
| Post graduate diploma | 7 |
| Type of palliative care inpatient service | |
| Direct care, mixed unit | 17 |
| Direct care, palliative care patients only | 10 |
| Consultative | 3 |
| Geographical location of workplace[a] | |
| Major city | 28 |
| Inner regional | 1 |
| Outer regional | 1 |
| Remote | 1 |
| Years of nursing experience | |
| 1–3 years | 2 |
| 3–5 years | 5 |
| 6–10 years | 2 |
| 11–15 years | 6 |
| 16–20 years | 5 |
| >21 years | 10 |
| Years of palliative care experience | |
| <1 year | 1 |
| 1–3 years | 5 |
| 3–5 years | 4 |
| 6–10 years | 9 |
| 11–15 years | 8 |
| 16–20 years | 1 |
| >21 years | 2 |

[a] Totals more than 30 because one participant worked in more than one geographical area.

## 3. Findings

There were 30 participants from nine specialist palliative care inpatient services in three Australian states (Table 1). Most were female ($n = 29$), worked in a major city location ($n = 28$) and had over five years palliative care nursing experience ($n = 20$). Twelve participants worked in

an advanced practice role, such as Clinical Nurse: Educator, Specialist, Consultant or Transitional Nurse Practitioner; and were more likely to have a relevant post-graduate qualification ($n = 8$) and longer length of palliative care experience. Twenty-five face-to-face and five telephone semi-structured interviews were conducted in late 2012 – early 2013. Duration of interviews averaged 21 min (range 7–62 min), with variation of duration reflecting whether or not participants could recall and recount a relevant incident. Although 27 participants stated the vignette was familiar to them, only 20 provided a detailed description of one or two incidents involving recognition and assessment of acute changes to awareness, cognition and perception, generating 28 clearly described incidents that were included for analysis. All interviews took place during office hours, yet participants described incidents that occurred over the 24-h period.

Thematic content analysis revealed the following two themes and six sub-themes:

(1) The delirium experience:
   (i) Patients' delirium: causes, presentations and outcomes
   (ii) Concern for the patient and self
(2) Nursing knowledge and practice in delirium recognition and assessment:
   (i) Challenges framing and naming observed changes
   (ii) Varying comprehensiveness of assessment
   (iii) Inter-personal relationships and communication are valued
   (iv) Uncertainty and challenges promote desire for learning.

These themes and sub-themes are outlined in further detail below.

### 3.1. The delirium experience

#### 3.1.1. Patients' delirium: causes, presentations and outcomes

The incidents described included a broad range of symptoms and scenarios that were congruent with delirium phenomenology, (Meagher et al., 2007), causation (Gaudreau et al., 2005, 2007; Lawlor et al., 2000) and reversibility in palliative care settings (Lawlor et al., 2000; Leonard et al., 2008). Participants attributed patient's delirium symptoms to a range of causes – often potentially modifiable ($n = 12$), such as: infection, hypoxia and medications (opiates, steroids, and an anti-psychotic). Complete resolution of delirium occurred in almost half ($n = 12$) the incidents, while in three incidents the patients' symptoms persisted. Most participants labelled symptoms as 'delirium' ($n = 14$), while few ($n = 2$) identified the subtype.

All incidents involved acute changes to patients' awareness, cognition and/or perception. Participants' noted that delirium symptoms were sometimes mild and fleeting or on occasion developed quickly with escalating severity:

> "He was alert and orientated on admission, but ...yesterday evening, he was starting to become a bit more unsettled and agitated. And then overnight he was quite paranoid and afraid that people were trying to keep him against his will. This morning... he is feeling that we're out to kill him and we're researching on him... and he's starting to use offensive language which is not in his normal personality." (P7)

Emotional manifestations of delirium, such as anger, agitation or fear were also described:

> "He was screaming at the top of his lungs... he was holding the buzzer, and he was saying that "That's a bomb" and he's angry with the nurses..." (P17)

Symptoms were sometimes initially attributed to patient's characteristics such as personality, but in retrospect recognised as having a physical cause which "... all made a lot of sense afterwards." (P16), and:

> "Thinking back...he started with ... rambling conversation and not being able to focus, and the vagueness, and other signs that we were just attributing to the medications or he's just a bit strange ... I think we made excuses for a lot of the little behaviours earlier on." (P27)

#### 3.1.2. Concern for the patient and self

Overwhelmingly participants expressed feelings of compassion, sadness, empathy or concern for patients experiencing delirium symptoms:

> "It's distressing to see a patient be fearful of you... they're terminally ill, they might be in pain, and then you add this to their situation where they're lying in bed terrified, frightened and don't want you to come near them...I don't mind how it affects me but it upsets me to see how distressed they are." (P7)

Patients' distress recalling their delirium experience and their subsequent concerns about their behaviour or mental health meant that participants' concern for their patients and provision of support continued even when the delirium episode had resolved:

> "She knew that she wasn't like quite right: ..."*I thought I was going crazy*"... "I know you did but you were perfectly safe, you know?" ... "*I know you kept telling me... but I still felt a bit mad*". (P26)

Participants described feeling an onerous responsibility and isolation "...it's my duty of care if something happens to her, you know?" (P30), particularly on evening or night duty:

> "I was only two years qualified at that stage and I was in charge of the ward that evening as well, and you don't have anyone to consult with ..." (P3)

The incidents provoked feelings of helplessness, fear, frustration, and feeling out of their depth when managing the fluctuating changes associated with delirium

> "You are wondering is it by talking to the patients, sitting with them and asking them what they are seeing and stuff like that, is that going to help? ... Sometimes you feel a bit isolated... a bit helpless... like: "Oh God, what am I going to do here?" (P3)

### 3.2. Nursing knowledge and practice in delirium recognition and assessment

#### 3.2.1. Challenges framing and naming observed changes

Participants had difficulties framing the neurocognitive changes they had observed and linking them to a potential delirium diagnosis:

> "Something about this patient, it's very unusual for her...we didn't know what's wrong with her..." (P30)

Symptoms were not explicitly integrated into a diagnostic or delirium framework:

> "We were talking about... somebody who came across as a bit confused and a little bit vague, but the consensus with the team was that that was all personality rather than medication induced. I thought that was interesting, I'm like: "How do you figure out that?" (P9)

Participants often expressed feelings of surprise, puzzlement and frustration when describing the period before confirmation of a delirium diagnosis:

> "The whole situation you were just feeling "Oh my gosh, what is it with him? How can we help him, why is he feeling like this? Is this part of his personality? ... He came in quiet and calm but is he showing his real self now?"...Trying to work out what it was... you were a bit frustrated not being able to solve the problem there and then." (P12)

Some incidents involved patients seeing deceased family members or heavenly visions; participants were uncertain whether this was delirium or a spiritual or paranormal event:

> "I had one patient that thought that they could see the gates, St Peter and the gates of Heaven. It was beautiful, she was in a great place, she was so happy and she said: "Can you see it?"...But is that delirium or is that a near death experience? Sometimes you don't know." (P16)

When it was perceived that there was a non-physical cause for observed symptoms and/or alternative terminology such as terminal restlessness or agitation was adopted, this impeded understanding of delirium:

> "What I've learnt is that we just don't pick it up. And that we often put everything into one bundle and we call it terminal agitation... I really believe that we really don't understand delirium at all." (P9)

> "It's hard to distinguish like delirium and then end-of-life terminal agitation... I don't know how to explain that one." (P30)

#### 3.2.2. Varying comprehensiveness of assessment

Comprehensiveness of patient assessment varied widely, from largely absent to broader assessments that were sensitive, holistic, inclusive of the patient, family and other team members and applied knowledge of potential causes of delirium symptoms (Nursing and Midwifery Board of Australia, 2006). When participants perceived that there was a spiritual or paranormal reasons for patients' report of hallucinations or illusions – such as a certain room on the ward being haunted – or when they attributed patients' perceptual disturbances to 'logical' misinterpretation of shapes or movement of objects in the room, they were less likely to undertake further assessment of the observed symptoms:

> "She is seeing somebody in her room, but there is nobody there. First I thought she was confused and then I thought ... she was watching my reflection from the window... I didn't ask her detail because she (was) dozing off, so I thought "Oh...a dream, half dream"... but I didn't really pay attention or like telling doctor straight away" (P6)

Participants noted that nurses who labelled patients' presentations as 'terminal restlessness' were also less likely to undertake further assessment and needed prompting to do so:

> "My (nursing colleague) was using the terminology (terminal restlessness)... And I said, "Have we done a PR? Have we done a bladder scan? Have we checked the urine? ... He's a culturally and linguistically diverse gentleman and maybe he's unable to communicate effectively"... The nursing staff got back to me – even though he'd been urinating he had a bladder of 1000 mls. So they've put a catheter in." (P11)

In some incidents, a basic physiological assessment of the patient was undertaken before informing the doctor of the observed changes:

> "The patient is confused and we did all the observations... temperature, and then blood pressure, and then respirations, oxygen saturations... initially I thought she was toxic to the opioids, so I checked the pupils...but she seems okay, she's not opioid toxic...(then) I told the doctor." (P30)

Participants working in advanced practice roles tended to describe more comprehensive assessment that included family member insights, the patient's phase of illness, goals of care, temporal pattern of symptoms and potential medication causes:

> "Well ...I think it all comes down to a really good and thorough assessment, ... knowing that person's story... non-medical and medical, speaking to the family... what was normal for her last week, what have we done since last week, where are we at with our disease process... all of those different things, how are we treating, what are we treating." (P26)

Although a small number of participants referred to cognition and delirium assessment tools such as the Mini-mental State Examination (MMSE) (Folstein et al., 1975) and the Confusion Assessment Method (CAM) (Inouye et al., 1990; Ryan et al., 2009), none described their application in their recalled incidents. Two participants stated their hospital's delirium policy gave them guidance on searching for potential physical causes of delirium or delirium symptoms (e.g. laboratory results, physiological measures, urinary retention). Otherwise, participants did

but inter-related concepts, and that nurse under-recognition of delirium as a syndrome – as opposed to delirium symptoms per se – is due to nurses' limited delirium diagnostic criteria knowledge (Steis and Fick, 2008). In our study, diagnostic criteria for delirium were not referred to during any of the incidents, with this absence contributing to nurses' puzzlement, worry and frustration continuing for a period of time (sometimes days) when they were not able to quickly make sense of what was happening for the patient, resolving only when it was determined – usually by the doctor – that delirium was the cause of the acute changes. Limited delirium knowledge and ability to apply the delirium diagnostic criteria to 'frame' delirium symptoms was similarly identified in another study exploring Australian palliative care, aged care, aged care psychiatry and oncology nurses' practice (Agar et al., 2012).

Although establishing any diagnosis is primarily a medical responsibility, nurses are required to develop understanding and expertise in recognising early signs and symptoms of prevalent syndromes and conditions and then proceed to comprehensive patient assessment, to effectively manage patients' care and communicate their findings to other members of the interdisciplinary team (Nursing and Midwifery Board of Australia, 2006; Registered Nurses Association of Ontario, 2003, 2004). Delirium is so intrinsically linked to illness or frailty, where the need for nursing care is greatest, so nurses ought have a major assessment role. Yet the syndrome's diagnostic criteria is predominantly held within the realms of psychiatry (American Psychiatric Association, 2000, 2013) and medicine, meaning that nurses are literally 'two steps removed' from this principal knowledge source and have unintentionally been excluded from developing a shared understanding of delirium, delirium recognition capabilities and contributing to the diagnostic process. This may in part explain why within the discipline there is suboptimal knowledge of delirium or understanding of the key nurse role in proactively recognising, assessing and managing this debilitating syndrome. To ensure all patients have access to exemplary care, all nurses must have equitable and timely access to evolving delirium knowledge and diagnostic criteria – such as recently revised and amended (American Psychiatric Association, 2013) – with translation and integration of this diagnostic criteria into everyday palliative care clinical practice and systems a critical first step towards developing nurses' delirium recognition and assessment capabilities (Registered Nurses Association of Ontario, 2004).

Reflective of gaps in nurses' delirium knowledge, failure to use correct delirium terminology has also been described as an "absence" within nursing delirium discourses (Kjorven et al., 2011, p. 332). Similarly, our study found that applying ambiguous terms such as 'terminal restlessness/agitation', commonly used in palliative care, also made it difficult for nurses to conceptualise delirium, link their observations of patients' symptoms to a delirium framework and often led to inaccurate presumptions of dying, further limiting further assessment and intervention. There is an urgent need for the palliative care community to cease using this imprecise terminology, because of conceptual confusion, imprecision, potential to miss delirium and subsequently for missed opportunities to reverse the syndrome and inappropriate use of other interventions (Heyse-Moore, 2003; Hjermstad et al., 2004; Milisen et al., 2005).

Our study revealed that the challenging, emotional experiences of caring for delirious patients was the catalyst for some nurses to seek delirium knowledge and/or to teach others in order to better understand and manage future patients' delirium. However, nurses also identified deficits in availability and access to delirium education relevant to their palliative care practice. Nurses across care settings similarly report knowledge and education deficits (Brajtman and Mc Pherson, 2006; Dahlke and Phinney, 2008; Flagg et al., 2010; Kjorven et al., 2011, p. 332), and highlights their need for more learning opportunities that are: linked to real patient scenarios, relevant to nursing and interdisciplinary palliative care practice, delivered at the unit or local level and evidence-based in content and delivery methods (Brajtman et al., 2008; Phillips et al., 2013). However, isolated education interventions to develop nurses' delirium knowledge are unlikely to be sufficient to optimise everyday nursing practice without additional systematic implementation of structured delirium recognition and assessment processes into local care settings (Balas et al., 2012; Registered Nurses Association of Ontario, 2003, 2004).

### 4.2. Recognition

'Recognition' is perception of sameness to something previously known (Macquarie Dictionary, 2006). In our study, many participants gave clear and nuanced descriptions of multiple delirium symptoms, causes and outcomes, revealing they recognised acute neurocognitive changes had occurred for recalled patients, as well as their sequent impact; yet not all promptly recognised observed symptoms as delirium. Despite use of a hypoactive delirium vignette (albeit with perceptual disturbance), many incidents involved patients experiencing rapid change and overt behaviours or distress. As such, they may be considered a more 'critical incident' and recognised and remembered by nurses (Breitbart et al., 2002). Alternatively, including hallucinations in the vignette may have prompted recall of a range of delirium scenarios, as perceptual disturbances occur more commonly in mixed delirium (Meagher et al., 2011). Regardless, the incidents were fundamentally representative of the spectrum of delirium presentations that occur in inpatient palliative care settings (Meagher et al., 2007) and described included more key domains, particularly acute onset, than previously described by palliative care nurses (Agar et al., 2012). These richer details may be due to inclusion of the vignette; and applying the CIT, which gave participants an opportunity to give a detailed recounting of a relevant patient incident.

Although participants believed that knowing the patient well and communicating with them and their family supported recognition of delirium symptoms, nurses' bedside interactions with patients will not always lead to them detecting delirium (Mistarz et al., 2011).

Aside from the challenge of recognising hypoactive delirium, not all patients with this syndrome will be known to nurses, able to communicate verbally or have family available, highlighting limitations of using unstructured delirium recognition approaches and sole reliance on patients' and family verbal capacity. Nurses are also less likely to document patients' delirium symptoms precisely if they do not use a structured screening process (Hare et al., 2008a; Steis and Fick, 2012).

In our study no nurse reported using a delirium screening tool, despite recommendations for use in high risk inpatient populations (Canadian Coalition for Seniors' Mental Health, 2010; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010; Registered Nurses Association of Ontario, 2003), their availability in some workplaces, and routine daily symptom screening being a requirement in most Australian palliative care inpatient settings (Aoun et al., 2011; Eagar, 2010). This unstructured approach to delirium recognition and screening not only contributes to palliative care nurses' uncertainty, worry and puzzlement about observed symptoms but also delays the commencement of appropriate intervention for patients to reverse the delirium and/or reduce its negative impact. It is evident that there is great scope to increase early recognition of delirium through routine screening by nurses, to ensure delirium is immediately considered as a possibility when acute symptoms first occur and promote ongoing assessment and timely communication of observed changes to team members.

### 4.3. Assessment

Nursing assessment is an evidence-based, comprehensive, systematic and structured process that applies knowledge, incorporates patient data from a variety of sources, considers the patient holistically, is conducted sensitively and supportively and confirms findings with the patient and health care team (Nursing and Midwifery Board of Australia, 2006). Applying this definition, it is clear that delirium assessment practice varied considerably, with several examples provided of inadequate or absent assessment. Comprehensive assessment of the patient with delirium symptoms ought include investigation of physiological status, effects of medications, contributing environmental factors and support and information needs of the patient and their family (Registered Nurses Association of Ontario, 2004). Attribution of spiritual or paranormal causes for perceptual disturbances; and/or conceptualisation of delirium symptoms as terminal restlessness/agitation each contributed to nurses failing to conduct this necessary level of patient assessment, underscoring the importance of developing nurses' knowledge of delirium diagnostic criteria, prevalence and negative impact on patients, so that delirium assessment and timely intervention is viewed as a palliative care nursing priority. It is not surprising that advance practice nurses, compared to bedside nurses, more often described elements of comprehensive assessment, as this likely reflects their more autonomous roles, longer duration of experience and attainment of postgraduate qualifications. However, in our study no nurses described using a risk assessment to identify predisposing and precipitating delirium factors (Canadian Coalition for Seniors' Mental Health, 2010; Lawlor et al., 2000; National Clinical Guideline Centre for Acute and Chronic Conditions, 2010), or undertaking a baseline cognitive assessment using a validated tool routinely for all new admissions. In almost all incidents the use of structured guidance and a systematic process for the assessment of the patient with delirium was not described. Considering both the complexity of delirium and requirement for nursing assessment to be comprehensive, systematic and structured, this is a clear gap in palliative care nursing practice.

### 4.4. Communication

Nurses in our study perceived the most effective and valued practices in delirium symptom recognition and assessment were knowledge of the patient, collaborative team communication and inter-personal relationships with patients, families and colleagues, particularly doctors. Proactive communication combined with an empathetic approach is valued by patients and families, who desire and are reassured by provision of delirium information and a calm, warm and respectful approach that promotes patient dignity (Brajtman, 2003; Greaves et al., 2008; Morita et al., 2007; Namba et al., 2007). Further, effective team collaboration, communication and functioning is known to improve processes and outcomes of care, including in palliative, chronically ill and frail populations (Abernethy et al., 2013; Tieman, 2007) and is pivotal to team members' health and morale (Palliative Care Expert Group, 2010). However, nurses frequently report feeling ignored or not heard when reporting their delirium observations to doctors (Al-Qadheeb et al., 2013; Kjorven et al., 2011, p. 332; Steis and Fick, 2008), potentially delaying intervention for the patient. This speaks to the need to design delirium communication strategies to strengthen interdisciplinary collaboration, mutual understanding, respect and effectiveness of care delivery (Vasilevskis et al., 2010).

### 4.5. The experience of nursing delirious patients

Across care settings, nurses universally feel incomprehension and discomfort when patients are delirious (Belanger and Ducharme, 2011). Similar to other studies exploring palliative care nurses' delirium experiences, this study has confirmed that nurses working in the palliative care setting experience distress when caring for patients with delirium (Agar et al., 2012; Brajtman and Mc Pherson, 2006; Breitbart et al., 2002). In our study, the predominant feelings nurses' expressed were compassion, concern and empathy combined with worry, frustration, fear, puzzlement, isolation, burden of responsibility and uncertainty: both about what might be happening to the patient and the best way to intervene. These findings reinforce the need for nurses to add structured delirium care processes into their daily practice and build their delirium recognition, assessment and management capabilities. Through development of delirium practice and knowledge, some of palliative care nurses' own professional support needs may

be addressed and their compassionate desire to help delirious patients better achieved.

### 4.6. Strengths, limitations and challenges

Like all qualitative studies these findings have limitations of transferability, as while the sample consists of nurses with varying roles and from several Australian palliative care units and different geographical locations, these nurses self-selected to participate and it is possible their experience reflects the views of nurses most interested in delirium. The strengths of this study include application of CIT, which allowed for brief, focused interviews and identifies effective, ineffective and missing practice, making it a feasible method to obtain nurses' perspectives and explore their professional delirium practice. While there were only a small amount of incidents compared to other CIT studies, this is likely related to the exploratory nature of the study combined with the focus on a narrow aspect of delirium care, namely inpatient palliative care nurses' recognition and assessment practices. Similar to previous CIT nursing studies (Bradbury-Jones and Tranter, 2008), a third of participants did not recount a specific clinical incident, despite the use of a vignette to prompt recall. Difficulty recalling a relevant incident may relate to under-recognition of delirium symptoms; alternatively, participants may not have been given sufficient time for recollection. As CIT also relies on participants' capacity to accurately recall and express past events and actions, the recounted incidents may not fully reflect the event or the extent of participants' actions. Adhering to the CIT's methods for data inclusion and analysis ensured rigour (Bradbury-Jones and Tranter, 2008; Butterfield et al., 2005), yet also resulted in exclusion of delirium insights of participants who could not recall an incident.

## 5. Conclusion

These findings expand our understanding of how nurses might actively engage in the building of better systems and clinical capacity, to better recognise and assess patients' with delirium symptoms in palliative care inpatient settings in the future.

### 5.1. Implications for practice, education and research

Given the prevalence and incidence of delirium in specialist palliative care setting (Hosie et al., 2013), a "high index of suspicion" by nurses is warranted (Le Grand, 2012; Registered Nurses Association of Ontario, 2003). It requires making delirium screening on and during admission routine practice, particularly when potentially delirium inducing interventions are introduced (Hosie et al., 2013; Rao et al., 2011). The extent of integration of systematic and structured processes for optimal delirium care within palliative care inpatient settings should be quantified. We need to further investigate whether implementation of a routine, structured delirium assessment process improves the capacity of nurses to recognise, assess and communicate patients' delirium symptoms (Detroyer et al., 2013); and importantly, which elements of practice change lead to better delirium outcomes and improved quality of life for palliative care patients and families (Gagnon et al., 2012). Advance practice nurses have an important role in defining, teaching and diffusing exemplar delirium practice within palliative care units. Further investigation of palliative care nurse delirium learning needs is required, as is subsequent development and testing of accessible delirium educational resources relevant to the context and team practice (Brajtman et al., 2008; Teodorczuk et al., 2013); for example, online delivery methods and their impact on knowledge, practice and patient outcomes (Phillips et al., 2013). Effective palliative care requires optimal collaboration and communication between team members, so interdisciplinary communication strategies – such as shared knowledge, language, tools and daily discussion (Balas et al., 2012; Brajtman et al., 2008; Vasilevskis et al., 2010) – to improve delirium recognition, assessment and intervention could be tested in the palliative care setting. For future practice and system interventions to improve delirium outcomes in palliative care populations, further knowledge of delirium epidemiology, contextual factors and patient, family and clinician perspectives of delirium care is needed. There is much work to be done to improve recognition, assessment and management of patients' delirium in palliative care and nurses must be part of the solution.

## Conflict of interest statement

The authors have no conflicts of interest to declare.

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## Ethical approval

The University of Notre Dame Human Research Ethics Committee – Reference number 0120585. The St Vincent's Hospital Human Research Ethics Committee – Reference number LNR/12/SVH/336.

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*Original Article*

# Identifying the Barriers and Enablers to Palliative Care Nurses' Recognition and Assessment of Delirium Symptoms: A Qualitative Study

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## Abstract

**Context.** Delirium is underrecognized by nurses, including those working in palliative care settings where the syndrome occurs frequently. Identifying contextual factors that support and/or hinder palliative care nurses' delirium recognition and assessment capabilities is crucial, to inform development of clinical practice and systems aimed at improving patients' delirium outcomes.

**Objectives.** The aim of the study was to identify nurses' perceptions of the barriers and enablers to recognizing and assessing delirium symptoms in palliative care inpatient settings.

**Methods.** A series of semistructured interviews, guided by critical incident technique, were conducted with nurses working in Australian palliative care inpatient settings. A hypoactive delirium vignette prompted participants' recall of delirium and identification of the perceived factors (barriers and enablers) that impacted on their delirium recognition and assessment capabilities. Thematic content analysis was used to analyze the qualitative data.

**Results.** Thirty participants from nine palliative care services provided insights into the barriers and enablers of delirium recognition and assessment in the inpatient setting that were categorized as patient and family, health professional, and system level factors. Analysis revealed five themes, each reflecting both identified barriers and current and/or potential enablers: 1) value in listening to

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patients and engaging families, 2) assessment is integrated with care delivery, 3) respecting and integrating nurses' observations, 4) addressing nurses' delirium knowledge needs, and 5) integrating delirium recognition and assessment processes.

**Conclusion.** Supporting the development of palliative care nursing delirium recognition and assessment practice requires attending to a range of barriers and enablers at the patient and family, health professional, and system levels. J Pain Symptom Manage 2014;48:815–830. © *2014 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

***Key Words***
*Assessment, delirium, inpatient, nursing, palliative care, screening, systems*

## *Introduction*

Delirium is a serious neuropsychiatric syndrome, characterized by acute and fluctuating changes to a person's attention, awareness, and cognition and resulting from physiological causes, such as those arising from serious illness, drug toxicity, or withdrawal.[1] Because of the underlying physiological abnormalities associated with delirium, it commonly occurs in unwell and/or elderly inpatient populations.[2,3] This includes those being cared for in specialist inpatient palliative care units/hospices, where delirium prevalence ranges from 13% to 43% at admission, 26% to 62% during admission, and 59% to 88% in the last weeks to hours of life.[4] Delirium is a critical event in a patient's illness journey. In the short term, delirium frequently causes great distress to the patient and their family,[5] as well as the clinicians caring for them.[6,7] Furthermore, patients who experience delirium have poorer outcomes related to increased risk of falls, pressure areas, further cognitive decline, institutionalization, and mortality[8–12]—all contributing to patients' poorer quality of life and higher health-care costs, with hospital costs for delirious patients two and half times the costs of those without delirium.[13]

Commonly used medications to manage pain and other symptoms, such as opioids, steroids, and benzodiazepines, are known iatrogenic causes of delirium,[14,15] and for many palliative care inpatients, delirium is reversible.[12,16] Clinical practice guidelines[2,3,17] affirm that timely recognition of patients' delirium is pivotal to implementing ongoing assessment, support, and treatment, including identifying and treating the cause, reducing the impact of the delirium experience and risk of related negative outcomes. Yet delirium is often poorly recognized, documented, and followed up by clinicians across inpatient settings[18–21]—including palliative care[22,23]—leading to inconsistent delivery of appropriate interventions to delirious patients.

Delirium underrecognition is linked to a range of factors, including clinician delirium knowledge gaps[24–26] that exist alongside the complexity of delirium phenomenology: widely differing presentations, with fluctuating symptoms, ranging degrees of severity, and manifestations of change to cognitive and psychomotor activity.[27,28] The predominance of the hypoactive subtype of delirium in palliative care—which has a quiet, lethargic presentation easily mistaken for other common problems in this population, namely fatigue or depression[22,28,29]—and the need for development of evidence into effective and feasible delirium screening, assessment, and treatment approaches in this unwell, frail, and dying patient population[30,31] also contribute to the problem of underrecognition.

Delirium underrecognition does not align with the World Health Organization definition of palliative care, which champions the need for impeccable assessment and preventative action to optimize patient-centered care and relief of suffering at the end of life.[32] Regardless of whether delirium is preventable or reversible for the individual patient, optimal person- and family-centered palliative care is best achieved through this accepted approach to the problems associated with a life-limiting illness. Developing the evidence for more effective strategies for delirium recognition, assessment, and

treatment is becoming increasingly recognized as a priority within palliative care practice development and research agendas.[30,31]

### *Building Palliative Care Nurses' Capacity to Recognize and Assess Delirium*

Palliative care nurses have a key role in delirium care because of their intimate patient contact over the 24 hour period and professional obligation to apply a systematic, patient-centered, and comprehensive approach to patient assessment.[33–35] Yet a combination of discipline-specific and systems factors limit delirium being consistently well recognized and/or managed by nurses, including high levels of distress and strain related to patients' delirium;[6,7,36] delirium knowledge deficits;[18,24,37] acceptance by some nurses of a "decline" philosophy about aging;[38] health service cultures that do not prioritize delirium care;[7] and absence of structured delirium recognition and assessment processes.[39–41] Lack of awareness of how to frame key symptoms within delirium diagnostic criteria[1,35,37] and a historic use of ambiguous terminology to describe delirium symptoms, such as "terminal agitation" or "terminal restlessness," have also been presented as reducing the impetus for palliative care nurses to consistently undertake comprehensive patient assessment and communicate their observations of patients' delirium symptoms to multidisciplinary team members.[35]

### *Knowledge Translation*

Building palliative care nurses' capacity to rapidly recognize delirium symptoms and consistently and comprehensively assess the patient is required.[2,3,17] The study described within this article was conducted as one component of a broader knowledge translation research program, which has an overall aim of improving the capacity of palliative care nurses to recognize, assess, and respond to patients' symptoms of delirium. Knowledge translation research aims to improve outcomes for patients through better integration of evidence into health-care services and the actions of health professionals.[42] It recognizes that knowledge exchange processes are multidirectional as clinicians have experiential and often tacit knowledge of the care settings in which they work.[43,44] To inform the later phase of our research, we first sought to engage with palliative care nurses and seek their perspectives about the context of inpatient palliative care and their delirium recognition and assessment practice, including what limits and supports this practice.

### *Aim*

The aim of this study was to identify nurses' perceptions of barriers and enablers to recognition and assessment of delirium symptoms within palliative care inpatient settings.

## Methods

### *Use of the Critical Incident Technique*

Our study was guided by the critical incident technique (CIT).[45] This research method collects and analyzes data related to participants' clearly recalled memories of a specific incident, to determine effective, ineffective, and missing practices, as well as factors or characteristics that help, hinder, or are critical to an activity.[45,46] This article reports on data specifically relating to participants' perceptions of barriers and enablers to delirium recognition and assessment in palliative care inpatient settings. As participant recruitment, data collection, and researcher reflexivity have been previously described in detail,[35] only a brief overview of study methods is provided here.

### *Participants*

Registered or enrolled nurses[47] working in Australian specialist palliative care inpatient services, with at least 12 months of clinical experience and more than three months of palliative care experience, were eligible to participate in this study.

### *Setting*

In Australia, specialist palliative care inpatient units are commonly situated as standalone wards within acute or subacute hospitals and use multidisciplinary teams to provide symptom management, respite, and terminal care for patients with life-limiting illnesses.[48] More than three-quarters of palliative care patients in Australia are aged more than 65 years and/or have a malignant primary diagnosis.[49]

*Recruitment*

Invitations to participate were distributed to nurses via 1) palliative care inpatient units and 2) a nursing social media site.[50] Nurses who were interested in participating after receiving this information communicated with the researcher (A. H.), either face-to-face on site or by telephone or e-mail if they were situated at a geographical distance and were then provided with a participant information sheet and consent form. Written consent was obtained from participants after their eligibility was confirmed and their questions about the study answered.

*Ethical Approval*

University and hospital ethical and governance approvals for this study were obtained before recruitment.

*Data Collection*

Data were collected using face-to-face or telephone semistructured interviews, conducted by A. H. Shortly before the interview, participants were provided with a vignette depicting a palliative care patient experiencing unrecognized hypoactive delirium symptoms.[35] The vignette and interview schedule (Table 1) were intended to elicit participants' memories of a similar critical incident and obtain their perceptions, experiences and practices in recognition and assessment of "acute changes to awareness, thinking, and perception" (key delirium diagnostic criteria at that time),[51] including their perspectives on how nursing practice might be improved in the future.

All interviews were audiotaped. A. H. completed field notes shortly after interviews, to record additional observations and insights and to summarize key points. Recruitment and interviews continued until no new information was being obtained and data saturation was apparent.[52]

*Data Analysis*

Interviews were transcribed verbatim. Data analysis was an inductive process using thematic content analysis.[52] Transcripts and field notes were read and reread, promoting immersion in the data (A. H.). Data were entered into an electronic spreadsheet, with interview questions providing an initial frame of reference for the multiple codes generated by the data. From this open coding (A. H., with independent coding of three random transcripts each by J. P. and E. L.), data relating to participant perceptions of barriers and enablers of nurse recognition and assessment of delirium symptoms were examined closely and categories of patient and family, health professional, and system levels identified. Preliminary themes were then generated (A. H. and J. P.) and discussed by the researcher team (A. H., J. P., E. L., M. A., and P. M. D.). Collaborative analysis and verification continued until the final themes were established, which aim to reflect participants' perceptions of barriers and enablers to nurse recognition and assessment of delirium symptoms in inpatient palliative care settings.[52] The Consolidated Criteria for Reporting Qualitative Research (COREQ) has guided the reporting of these qualitative data.[53]

## Results

Thirty nurses from nine specialist palliative care inpatient services across three Australian states participated (Table 2). Twenty-five face-to-face and five telephone interviews, averaging 21 minute duration (range seven to 62), were conducted in late 2012 to early 2013. Despite varying capacity of participants to recall and recount specific delirium incidents, all were familiar with the challenges of nursing palliative care patients experiencing delirium symptoms and provided insights into delirium recognition and assessment practice in this setting. Thematic content analysis revealed a range of barriers and enablers for delirium recognition and assessment.

Overall, participants more frequently described what helped rather than what hindered their practice, with "opposing" current or potential enablers for most barriers identified. For example, although some participants identified as a barrier a lack of respect from others in the team about their clinical observations, a greater number of participants identified that the presence of mutual respect between team members enabled more effective delirium recognition and assessment.

*Table 1*
**Vignette and Interview Schedule**

| Delirium scenario |
|---|
| Mrs. X is admitted to your palliative care unit on Monday. She is widowed, aged 81, lives alone and her diagnosis is advanced lung cancer. The reason for admission is for symptom management, as she has escalating pain. She has a son and daughter, but she is unaccompanied by any family or friends at admission. Medical and nursing admission processes are completed. Mrs. X was independent with ADLs prior to admission. She shares a four-bed room with 3 other female patients. |
| Her opioid and adjuvant doses are increased after admission and by day 3 her pain appears to be improving. |
| Mrs. X is a quiet, cooperative lady who displays no signs of agitation, but is noted to be a little vague in her verbal responses. She interacts only occasionally with the other patients in the room. She sleeps for intervals during the day, and is sometimes slow to rouse. Night staff report that she is awake for periods of time each night. When awake, she sits quietly and watches what is happening in the room. |
| Her son visits her each evening after he finishes work. On the evening of the fourth day of admission, he speaks to the nurse on duty and tells her that his mother has told him that she can see a dead man in the corner of the room, and that it has been there since she arrived on the ward. He also reports that his mother is not as clear in her speech and thinking as is usual for her. |
| The nurse speaks to Mrs. X about this. Mrs. X says she has been wondering why no one has talked about this man and that she was too frightened to report what she was seeing, in case people thought she was "crazy." She reveals that she finds the sight of the dead man very disturbing, and is worried she is "losing her marbles." She also reports she is finding it harder to concentrate and remember simple things. |
| **Interview schedule** |
| Introduction to the interview |
| "Thank you for agreeing to participate. The interview may take about 20 minutes. It will be audio-taped and I may also take some notes during the interview. Is that OK with you? |
| During the interview I will ask you some questions about your experience in nursing a palliative care patient who has acute changes in their awareness, thinking and perception, with the focus on how nurses recognise and assess these changes. The interview is not meant to be a test, we are mainly looking for insights into what nurses think are the most important things to do when caring for patients with these changes. You might find you feel a bit nervous, or as you recall your experiences it is possible this may bring up some feelings for you. It is OK to not answer all of the questions, or to ask for a break if you need it. Remember, whatever you say in the interview is confidential. |
| Have you had a chance to read the case study? Are you ready to start now? |
| Interview questions |
| 1. Does this case study reflect a situation you have observed or experienced recently in your own clinical practice? |
| 2. Can you tell me about one particular patient situation in detail that this case reminded you of? |
| 3. Can you tell me how you felt at the time about this situation? |
| 4. Can you tell me what did you do about this situation? |
| 5. In looking back on that situation, is there anything you would do differently? |
| 6. Thinking about the future, do you have any suggestions for what we as nurses could do to better recognise and manage the situation? |
| Conclusion of the interview |
| "Thank you for your time—I really appreciate your input. Do you have any further comments or questions? Remember, you can contact me by phone or email if you want to discuss the interview or study." |

These barriers and enablers existed at the patient and family, health professional, and system levels and generated five distinct themes:

1. Patient and family level:
   i) Value in listening to patients and engaging families;
2. Health professional level:
   ii) Assessment is integrated with care delivery;
   iii) Respecting and integrating nurses' observations;
   iv) Addressing nurses' delirium knowledge needs; and
3. System level:
   v) Integrating delirium recognition and assessment processes.

These themes are described in detail in the following and summarized within Table 3.

### *Barriers and Enablers at the Patient and Family Level*

*Value in Listening to Patients and Engaging Families.* Participants acknowledged the challenges inherent in recognizing and assessing delirium: "It's a very difficult symptom, or condition, to diagnose and then treat …" (P16). Participants believed patients were often reluctant to report their symptoms because of embarrassment or fear of being seen as 'crazy.' Another perceived barrier was the use of cognitive assessment processes requiring lengthy quizlike questioning of patients, such as those routinely used in Australian inpatient settings,[54] as these were perceived to be too burdensome

*Table 2*
**Characteristics of the Sample ($n = 30$)**

| Characteristic | Number |
|---|---|
| Gender | |
| Female | 29 |
| Male | 1 |
| Age (yrs) | |
| 21–30 | 3 |
| 31–40 | 11 |
| 41–50 | 9 |
| 51–60 | 6 |
| 61–70 | 1 |
| Position title | |
| Registered nurse | 16 |
| Clinical nurse specialist | 6 |
| Enrolled nurse | 2 |
| Clinical nurse consultant | 2 |
| Nursing unit manager | 2 |
| Clinical nurse educator | 1 |
| Nurse practitioner candidate | 1 |
| Highest qualification | |
| Certificate | 5 |
| Diploma | 4 |
| Bachelor | 9 |
| Postgraduate certificate | 9 |
| Postgraduate diploma | 7 |
| Type of palliative care inpatient service | |
| Direct care, mixed unit | 17 |
| Direct care, palliative care patients only | 10 |
| Consultative | 3 |
| Geographical location of workplace[a] | |
| Major city | 28 |
| Inner regional | 1 |
| Outer regional | 1 |
| Remote | 1 |
| Years of nursing experience | |
| 1–3 | 2 |
| 3–5 | 5 |
| 6–10 | 2 |
| 11–15 | 6 |
| 16–20 | 5 |
| >21 | 10 |
| Years of palliative care experience | |
| <1 | 1 |
| 1–3 | 5 |
| 3–5 | 4 |
| 6–10 | 9 |
| 11–15 | 8 |
| 16–20 | 1 |
| >21 | 2 |

[a]Totals more than 30 because one participant worked in more than one geographical area.

for palliative care patients who were frequently frail and fatigued:

> "What date is it? Where are you? Do you know this? What year? Who's the prime minister?" … Let's be a little bit more gentle and understanding when we're trying to pick up any sort of confusion in patients … fatigue is a big factor for our patients, where they just don't have the energy any more to do a lot of the things that we ask them, or to answer the questions. (P16)

It was suggested that the challenge of recognizing and assessing delirium could be better addressed if nurses communicated caringly with patients, to establish rapport and trust. Although this process also involved questioning the patient, these questions instead centered on patient comfort:

> Just communicating with her a little bit more, finding out why she's awake. "Is there anything more we can do? Is something worrying you? Are you uncomfortable?" All those basic things, talking to her, just sitting for a few minutes in the middle of the night beside the bed and just holding her hand. (P13)

Building relationships meant that even in difficult circumstances, patients were more likely to share what they were experiencing, "People don't talk about that unless they feel confident and trusting in your care." (P04). Participants also described how they engaged other team members who might spend further time with patients, as a strategy to help them share their concerns:

> I'd probably get pastoral care to go and have a chat to her and see if there's anything worrying her … they let the person take the time that they need to talk. (P14)

Engaging with family members was considered important because their observations provided valuable insights about changes to patients' awareness, cognition, and perception, contributing to earlier recognition and assessment of the delirium symptoms:

> Families often recognize it the most … changes in sleep cycles, not recognizing family when they come in or being overly tired … (P19); and

> Family do give feedback too … if they are in every day they engage with the patient and they say: "Look, there is something different about them today." Even if they are not hallucinating, there is something different: "She's more drowsy" and we act on that too. (P24)

Participants proactively sought additional information from family, to assist with their assessment process, and asked questions such as "Do they say that? Is that normally a problem for them?" (P07); and "Has this

*Table 3*
**Summary of Nurses' Perceptions of Barriers and Enablers to Delirium Recognition and Assessment in Palliative Care Inpatient Settings**

| Level | Barriers | Current Facilitators | Potential Facilitators | Resulting Themes |
|---|---|---|---|---|
| Patient and family | • Delirium is difficult to recognize<br>• Commonly used cognitive assessment tools can be burdensome for the patient | • Establishment of rapport and trust with the patient<br>• Seeking family knowledge of the patient's baseline function, cognition, and perception | | 1. Value in listening to patients and engaging families |
| Health professional | • Time and workload pressures<br>• Lack of respect for nurses' observations<br>• Gaps in nurses' delirium knowledge and erroneous beliefs<br>• Lack of delirium education opportunities relevant to nursing and palliative care practice | • Discreetly conducting patient assessment during delivery of direct patient care<br>• Nurses' observations are respected, responded to, and integrated into multidisciplinary team interactions | • Provision of delirium learning opportunities for nurses, linking evidence to patient scenarios, relevant to nursing and palliative care practice and delivered locally | 2. Assessment is integrated with care delivery<br>3. Respecting and integrating nurses' observations<br>4. Addressing nurses' delirium knowledge needs |
| System | • Minimal integration of delirium guidance tools | • Presence of in-hospital delirium guidelines supports practice and delivery of delirium education to other nurses | • Development and/or integration of delirium guidance tools, for example, risk assessment, clinical pathways, screening tools | 5. Integrating delirium recognition and assessment processes |

happened before? Have they been on these medications for a long time? Is it something new?" (P13).

Participants identified that barriers to recognizing and assessing delirium at the patient level were challenges inherent to the complexity of delirium, patient reluctance to report troubling changes to their cognition and perceived burden of cognitive assessments requiring lengthy questioning. Enabling factors included establishment of trust and rapport between patients and team members through verbal and nonverbal communication of caring and active engagement of family members in the patient assessment process.

### *Barriers and Enablers at the Health Professional Level*

*Assessment Is Integrated with Care Delivery.* Participants identified time and workload pressures as a barrier to delirium recognition and assessment: "Because, no way, you don't (have) an hour or two of your day to try and find out what is going on." (P01). But despite time and workload pressures, participants strived to focus their attention on individual patients during care delivery. This participant believed that it was in making an explicit decision to focus, listen and talk with patients during physical care delivery—rather than be distracted by the many nursing tasks needing completion—that they came to a better understanding of what was happening for the individual:

> You can give a patient a shower in a relaxed, peaceful manner, taking time to have a conversation with them, or you could be like a mad woman and try and do two showers at once and one wash, and be thinking about the next thing … and the patient's talking to you and you're not listening … (P04)

Personal contact and interaction with the patient enabled participants to identify changes and conduct ongoing and continuous assessment:

> Whilst you're multi-tasking … assessing, talking, picking up cues, learning their verbal and non-verbal cues … you're going in and assessing the patient every time you're interacting with them. (P11)

Assessing patients for the presence of delirium symptoms occurred as an 'on the run' process, rather than as a discrete, structured delirium

assessment per se. For example, observing patients' capacity to undertake activities of daily living informed participants whether they may be experiencing delirium:

> Watching people's coordination and how they're going with feeding themselves … If someone was able to brush their teeth the day before and now today they're not sure what they're doing, something's going wrong, in their basic motor tasks. And why? Question why they're not able to do that today. (P07)

This included assessing patients' response, attention, and awareness during nursing care:

> Showering them or getting them ready for a meal or giving them their medication, just to how they're reacting or not reacting to you. (P14)

So despite some participants considering having several patients to care for and many tasks to complete as a barrier to delirium recognition and assessment, most believed that integrating a continuous observation and assessment process during patient interactions and delivery of care enabled them to observe and assess changes to patients' function and the presence of delirium symptoms. However, no participant described recording these observations and assessments within any structured delirium tool; instead, they proceeded to report any concerns to either a more senior nurse or the doctor.

*Respecting and Integrating Nurses' Observations.* Perhaps because of this absence of structured explicit delirium assessment, some participants indicated that other team members—particularly doctors and other nurses—did not always appear to respect their clinical observations. This, in turn, appeared to restrain participants from feeling confident and effective in their delirium recognition and assessment role:

> We communicate … what's happening with the patients … you make suggestions to doctors or you bring it to their attention … (but) I think the doctors could be a little more respectful of the value of the nurses' information and then nurses more respectful of (our) own opinions. (P04)

Whereas, "if everyone can work as a team" (P13) this enabled participants' initial reporting of delirium symptoms, and they believed this led to further multidisciplinary assessment and improved patient outcomes. Deliberate and conscious efforts to engage with medical colleagues were made to promote teamwork, rapport, and mutual respect:

> We've just got a new resident and registrar at the moment so it takes a little bit of time to build a rapport, that they can see, "Oh look these (nurses), they're pretty good" … then you're all aiming for the same thing with the patient. Saying hello to them in the morning, "Hi, good morning, how was your weekend?" Not just all walking past each other. (P13)

There were examples where relaying observations to the doctor and being listened to contributed to resolution of patients' delirium:

> I then waited until the consultant came in in the morning and spoke to him directly … He actually listened to me … she ended up on IV (intravenous) antibiotics and reduction in her opioids and she returned to normal and she went home. (P11)

Nursing participation in multidisciplinary team meetings provided opportunities for them to communicate their patient observations:

> There's the multidisciplinary meeting which they have once a week … a lot of the nursing staff attend … it's amazing the insights that nurses can give … when you're working with (patients) for eight hours a day … (P15)

As did nursing participation in medical ward rounds:

> We were doing ward rounds and I relayed that on to the doctor … he worked through a few things and pointed out that she had this delirium … we can interrupt the ward round if we've noticed something over the last 24 hours, any of the nursing staff can have input and say something, that works really good. (P16)

A daily team meeting facilitated prompt recognition of changes to patients' condition and a multidisciplinary response:

> We communicate effectively with … a full MDT (multidisciplinary) meeting … all week days to get a proper picture of how the patients are travelling, rather than waiting a few days … and we battle those clinical needs and issues as we see them. (P28)

This finding identifies that for some participants, feeling they were not respected or listened to when they reported their observations of changes in patients awareness or cognition was a barrier to recognition and assessment of patients' delirium; whereas when participants believed that when they were respected and listened to by others in the team and had regular opportunities to report their observations, this enabled more timely and effective multidisciplinary responses to patients' delirium symptoms. However, team strategies specifically designed for delirium recognition and assessment were not described.

*Addressing Nurses' Delirium Knowledge Needs.* Participants acknowledged that gaps in nurses' delirium knowledge were a major barrier to delirium recognition and assessment: "I just think as nurses we are not trained enough in dealing with delirium" (P03), and "I think it's an area where we haven't really even begun to … understand—that's probably what I've learnt about delirium!" (P09). Although having cared for many patients with delirium, several participants conceded their own knowledge deficit:

> Assessment is usually crucial, but it's just knowing how to assess … I don't know what the questions would be. (P01)

They also acknowledged that beliefs that a patient's personality or old age explained delirium behavior were a barrier to prompt recognition: "Don't just think: 'It's old age'" (P07) and:

> How do you get you know a person to change their thinking from "That's a batty old lady" to "Oh, well there might be something else going on there …?" (P19)

This participant highlighted how her lack of knowledge about the potential for steroid medication to precipitate delirium resulted in feelings of bewilderment about a patient's agitated behavior and delays in recognition of his delirium:

> He had just started to go really off and get aggressive, agitated, wanting to get out of here, just wasn't himself. It took us a little while to figure it out but it was actually the dexamethasone … the whole situation you were just feeling "Oh my gosh, what is it with him? How can we help him, why is he feeling like this? Is this part of his personality?" (P12)

Participants overwhelmingly believed delirium education opportunities for nurses were needed and that these needed to be tailored to nursing or palliative care practice:

> I went to the delirium study day … I found it was very medical based, I think we need more our level … In palliative care courses or when you join the ward … in-services … to help nurses along, educate them a bit more in the area. (P03)

Most expressed a preference for future delirium learning opportunities that were linked to actual patient scenarios, relevant to both nursing and multidisciplinary palliative care practice, and delivered at the unit or local level:

> I think that giving staff the time to personalise it … "This is the evidence based practice" and linking it with a recent case, and saying: "So we need to incorporate this … let's look at this case." (P09)

Debriefing opportunities around episodes of missed delirium could enable valuable team delirium learning scenarios:

> As a team … identify: "OK, so these things happened, but we didn't notice it, we didn't attribute that to the fact that maybe they were delirious" … More opportunities to debrief and break things down and look at the first trigger, like: Where was that? Where did we miss it? What was the first trigger? (P09)

This theme highlights that participants readily acknowledged delirium knowledge deficits, erroneous beliefs and limited education opportunities within nursing practice as barriers to optimal delirium recognition and assessment; while they believed their practice could be enabled through development and local delivery of delirium education,

particularly using debriefing and "real-life" patient scenario learning approaches.

*Barriers and Enablers at the System Level*

*Integrating Delirium Recognition and Assessment Processes.* Translation of delirium knowledge into palliative care nurses' routine practice might also be regarded as a system-level factor. For example, despite comprehensive delirium assessment in frail, unwell, and elderly patients being a complex multifaceted process and the availability of delirium clinical practice guidelines,[2,3,17] very few participants reported ready access to protocols, guidelines, or integrated systems that translated this delirium knowledge into their workplace—in fact, they identified their absence:

> Unfortunately the (admission) assessment doesn't ask about delirium or depression … and it's not a daily thing that we screen. (P09)

In the few settings where delirium guidelines were embedded within the hospital as a whole, participants described the value of these documents, for both their own practice and when delivering delirium education to other nurses within their workplace:

> The palliative care service itself has come up with delirium guidelines for the palliative patient … (that are) policy for the whole hospital … when I'm doing education I say to people: "This is a copy of this document about delirium, take it away and read it, it's really interesting, it will inform your practice and how you do things. (P21)

Most participants believed that integration of delirium screening or assessment tools, care plans, or a delirium "clinical pathway" (P30) into the inpatient setting would result in better delirium recognition and assessment practices by nurses:

> What about a delirium risk assessment tool … for the frail aged particularly … something that we can create as a screening tool that can give an alert system (P19)

> I think there should be screening in place. I would like to see in the future that there is a really good assessment that we can do … that we can say, "OK, this person possibly is delirious, let's go through the assessment and then we can know for sure." (P09)

## Discussion

This study provides insight into multiple level factors within palliative care inpatient settings influencing the capacity of nurses to recognize and assess patients' delirium. Several findings are consistent with known barriers to nurse recognition of delirium across many settings of care, such as incomplete delirium knowledge;[55] erroneous assumptions about 'normal' cognitive function in aging;[38] perceptions of not being listened to when communicating delirium symptoms;[56] limited delirium educational opportunities for nurses;[18,55] and absence of structured delirium screening and assessment processes within their workplaces.[39–41] Addressing each of these barriers is required to optimize palliative nurses' delirium practice. But less frequently reported in the literature have been nurses' perceived delirium practice strengths and/or factors that they believe support them to contribute to effective delirium management.[57] Our study identifies a number of perceived practice enablers and opportunities to strengthen nurses' engagement in early recognition and comprehensive assessment of delirium in palliative care settings. These enablers include establishment of trust and rapport with the patient; actively obtaining the insights of family; integrating assessment into direct patient care; working within a collaborative, respectful, and dynamic team environment; and the potential benefit of integrating delirium education and routine systematic processes within local care settings.

Our findings related to interpersonal interactions are important because these remind us of the primacy of positive caring relationships with others in the provision of person-centered and compassionate end-of-life care, be it with patients, family members, or between colleagues.[17] Patients and family members similarly value care that demonstrates respect, sensitivity, and maintenance of dignity during an episode of delirium.[7,58,59] However, effective recognition and assessment of delirium cannot be achieved solely through clinicians' bedside interactions with patients—however compassionate or present—nor respectful team relationships

generally, as these qualities alone do not sufficiently provide the explicit honed focus required to distinguish delirium,[60,61] particularly when the complexity of palliative care patients' symptom management and holistic care needs is considered. As structured team conversations have positively impacted on other outcomes for palliative care patients,[62] there is great potential benefit in building multidisciplinary team members' delirium knowledge,[63] adopting a shared delirium language shaped by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) criteria[1] and creating opportunities to routinely explicitly discuss patients' delirium status. In another care setting, whole team interventions focused on improving delirium care demonstrated that when nurses adopt the role of performing routine, structured, systematic delirium assessment processes, this better informs team decision making around the individual patient care needs.[64] Delirium interventions such as these inform us of how we might develop similar strategies within multidisciplinary palliative care practice.

Another important finding related to team communication is that palliative care nurses engage in discreet delirium observation and assessment of patients while undertaking daily care tasks, such as showering, giving medications, and talking with patients. This tacit process may be understood and valued by nurses but may not be discernable to others in the team. It is unlikely that nurses will achieve consistent and effective communication of patients' delirium to others if they fail to undertake and document a comprehensive delirium assessment, as having a common assessment framework and language is another key factor crucial to improving palliative care patient outcomes.[65] Performing, and then communicating, an unstructured delirium assessment might then explain why some nurses in our study reported feeling a lack of respect for and response to their observations from team members, which then forms a barrier to effective team approaches to timely delirium recognition, comprehensive assessment, and intervention—both at that point in time and likely for future similar patient events. Other nurses have similarly reported feeling dismissed or ignored when reporting delirium symptoms to physicians,[56,66] indicating this communication issue is a real barrier to delirium care and again underlining the imperative to better define and strengthen nurses' delirium observation and assessment role and processes for effective team communication, tailored to the specific requirements of each specialty or setting of care.

It is encouraging that nurses in this study believed adoption of delirium guidance tools in their workplaces would improve practice and patient care outcomes, as this reflects recommendations within delirium clinical practice guidelines.[2,3,17] Numerous delirium tools exist, such as risk assessments,[3,67,68] screening and assessment tools,[69] clinical pathways,[70] and algorithms.[71] Although delirium screening tools have not yet been extensively developed, tested, or implemented in palliative care settings,[4,72] there is emerging evidence that their routine use by nurses in palliative care inpatient settings is effective and feasible. Rao et al.[73] reported that palliative care nurses successfully integrated screening into their daily practice using an observational and shortened version of the Confusion Assessment Method (CAM),[74] whereas Gagnon et al.[75] reported the successful implementation of the Confusion Rating Scale[76] by bedside nurses in seven palliative care units/hospices during a three year delirium prevention trial. Of note, a full CAM was applied in only 39% of participants in the latter study because of patients' impaired consciousness or perceived burden of the structured interview,[75] highlighting limitations of the full CAM version in palliative care settings. Most recently, Detroyer et al.[77] applied the Delirium Observational Screening Scale [78] in a palliative care unit, reporting good diagnostic validity and nurse perception that the tool was user friendly; however, it relies on patients being able to communicate verbally, limiting its applicability across the whole of this inpatient population.

Informed by these prior studies and views of nurses who participated in our study, implementation of structured delirium processes into routine palliative care nursing practice requires mindfulness of the need to choose tools that are appropriate and low burden for most palliative care patients; inclusive of the observations and input of family members; incorporative of nurse observations; and brief and comprised easily memorized components that can be rapidly internalized and applied by

nurses during each patient interaction. Additional tools meeting all or some of these criteria include the Nursing Delirium Screening Scale, a one minute tool evolved from the Confusion Rating Scale, which captures nurses' patient observations over the preceding eight hours of their shift;[79] the combined Delirium Triage Screen and Brief Confusion Assessment Method, validated for rapid delirium screening in the emergency department;[80] the Single Question in Delirium, a single question asked of family members on admission to an oncology setting;[81] and the Recognizing Active Delirium As a Routine (RADAR), a three minute screening tool that captures potential delirium symptoms observed by nurses during medication administration.[82] As none of these tools have been validated in palliative care populations, further research testing their feasibility and reliability is required.

Similar to other studies,[55,56,83,84] nurses in our study desired more delirium education and preferred that it be delivered within the clinical setting and tailored to palliative care nursing practice. Improvements in nurses' delirium knowledge, confidence, documentation, and detection of delirium have been demonstrated across elderly acute, postacute, and palliative care inpatient settings through educational and practice change interventions.[63,85–87] Further research into palliative care nurses' delirium knowledge needs and developing and evaluating targeted interventions that build their delirium capabilities is urgently required.

### *Strengths and Limitations*

Although perceptions of Australian palliative care nurses in various roles, workplaces, and geographical locations have been captured in this study, nurses self-selected to participate, so a limitation is that participant views may represent those most interested in delirium. Almost all participants were female, and although likely to be generally representative of Australian nurses, this is also a potential limitation of the sample. Although the study was guided by the CIT, for data inclusion we deliberately choose to include all participants' insights relating to delirium recognition and assessment barriers and enablers, consistent with the overall intention of CIT to reveal factors that help or hinder an activity.[45,46] Adopting this approach has provided valuable insights into nurses' views on barriers and enablers to their current and future practice, with the caveat that these qualitative findings may not be transferable to other regions and settings of care. Participants were not directly asked to describe barriers and enablers to their delirium recognition and assessment practice, which may limit the completeness of our findings. Including the voices of participants through the use of verbatim quotes and independent coding of six random transcripts by two additional coders during data analysis strengthen the reporting and analytical rigor of our study.[52]

## *Conclusion*

The findings of this study reveal that palliative care nurses are striving to provide effective, compassionate and person-centered care to patients experiencing delirium symptoms, but that they are doing so with limited delirium knowledge and educational opportunities and in the absence of structured screening, assessment, and team processes. These nurses also identified how their delirium practice might best be developed. Given the prevalence of delirium experienced by palliative care patients, addressing the multilevel factors that impact on nurses' ability to optimally recognize and assess patients' delirium symptoms is critical to advancing delirium care in this specialist setting. This study provides valuable information about the numerous opportunities to improve nursing and multidisciplinary team palliative care practice through more systematic application of existing evidence. Consistent with the processes of knowledge translation, findings will inform the next stage of our research: an intervention aiming to build palliative care nurse capacity to recognize, assess, and respond to patients' symptoms of delirium.

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ORIGINAL ARTICLE

# Nurse perceptions of the Nursing Delirium Screening Scale in two palliative care inpatient units: a focus group study

Annmarie Hosie, Elizabeth Lobb, Meera Agar, Patricia M Davidson, Richard Chye and Jane Phillips

**Aims and objectives.** To explore nurse perceptions of the feasibility of integrating the Nursing Delirium Screening Scale into practice within the inpatient palliative care setting.

**Background.** Delirium occurs frequently in palliative care inpatient populations, yet is under-recognised. Exploring feasibility of delirium screening tools in this setting can provide insights into how recognition can be improved.

**Design.** This was a qualitative study using a focus group methodology.

**Method.** Four semi-structured focus groups were conducted with 21 nurses working in two Australian palliative care units. Focus groups were digitally recorded and transcribed verbatim. Thematic content analysis was used to analyse the data.

**Results.** Three major themes were identified: (1) Delirium screening using the Nursing Delirium Screening Scale is feasible, but then what? (2) Nuances, ambiguity and clinical complexity; and (3) Implementing structured processes requires firmer foundations. Themes describe how nurses perceived the Nursing Delirium Screening Scale to be an easy and brief screening tool which raised their awareness of delirium. They were largely willing to adopt it into practice, yet had uncertainty and misunderstandings of the tool specifically and delirium screening generally, application in a palliative care context, interventions for delirium and impact of screening on medical practice.

**Conclusion.** The Nursing Delirium Screening Scale is feasible for use in a palliative care inpatient setting, but requires investigation of its psychometric properties before routine use in this patient population.

**What does this paper contribute to the wider global clinical community?**

- Despite the prevalence of delirium in palliative care inpatient populations, screening tools are not used routinely to ensure early recognition by the team.
- Findings from this focus group study indicate that the Nursing Delirium Screening Scale is feasible in this setting, supporting further investigation of its psychometric properties when used in palliative care.
- Multifaceted implementation approaches, such as nurse education, leadership and interdisciplinary collaboration, are also needed to optimise the impact of a delirium screening tool in palliative care practice.

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**Relevance to clinical practice.** Nurses require understanding of delirium, tailored guidance and a united approach with doctors to support their effective use of a delirium screening tool in the palliative care unit. Delirium practice change in this setting will also require nurses to become more active leaders and collaborators within their interdisciplinary teams.

**Key words:** assessment, delirium, focus group, hospitalised patients, nursing, palliative care, screening tools

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## Introduction

Delirium occurs in around one in five hospitalised patients and has serious implications for patients, families, clinicians and the health care system (National Clinical Guideline Centre for Acute and Chronic Conditions 2010). The disorder manifests as acute change to attention and cognition arising from physiological disturbances (American Psychiatric Association 2013). During an episode, patients' quality of life, communication, decision-making capacity and function are impaired and patients often recall their delirium experience as a time of great distress (Australian Commission on Safety and Quality in Health Care 2013). Delirium contributes to poorer patient outcomes, including increased length of hospital stay, nursing home admission, risk of falls and further cognitive decline and mortality, and contributes to higher health care costs. Caring for delirious patients is distressing for family members and clinicians. Early recognition, careful assessment and treatment of precipitants and evidence-based and compassionate responses by clinicians are essential for the quality and safety of patient care (Australian Commission on Safety and Quality in Health Care 2013).

## Background

Palliative care inpatients also often experience delirium, with prevalence reported as 13·3–42·3% at admission, 26–62% during admission and 58·8–88% preceding death (Hosie *et al.* 2013). Despite its frequent occurrence delirium is under-recognised by palliative care teams, particularly for patients with the hypoactive subtype, whose lethargy may be attributed to fatigue or depression (Fang *et al.* 2008). Early detection of delirium is vital to ensuring timely assessment, reversal wherever possible and supportive care (Lawlor & Bush 2014). Up to one half of palliative patients may have a potentially treatable precipitant (e.g. infection or psychoactive medications commenced for symptom control) and there are numerous nonpharmacological supportive interventions for delirious patients and their family (Canadian Coalition for Seniors' Mental Health 2010; Lawlor & Bush 2014). Palliative care assessment includes careful discernment of the patients' prognosis, their goals of care and the burden versus benefit of investigation and intervention. Clear communication with the patient, family and team supports informed, shared and ethical decision decision-making (Lawlor & Bush 2014). Impeccable assessment is especially important for delirious palliative care patients, due to the serious implications of delirium, patients increased vulnerability and as sedation with various benzodiazepines may be used to manage intractable agitated symptoms in the dying phase. Sedation of dying patients with refractory symptoms is a clinically and ethically complex practice that lacks high-level evidence for its efficacy and harmful if used precipitously (Cherny & Radbruch 2009).

### Promoting recognition of delirium through routine screening

Routine screening within high-risk populations is the first step towards improved delirium care (National Clinical Guideline Centre for Acute and Chronic Conditions 2010). Symptom and outcome measures, such as the Symptom Assessment Scale, the Edmonton Symptom Assessment System and the Palliative care Outcome Scale (Eagar 2010, National Palliative Care Research Center 2013) are used by palliative care services internationally, but do not include delirium screening. Brief, low-burden delirium screening tools developed for nurses are potentially useful additions to these routine measures.

Examples of tools fitting this brief are the Nursing Delirium Screening Scale (Nu-DESC) (Gaudreau *et al.* 2005), the Delirium Observation Scale (DOS) (Schuurmans *et al.*

2003), the Single Question in Delirium (SQiD) (Sands *et al.* 2010) and the 'Recognizing Active Delirium As a Routine' (RADAR) (Voyer *et al.* 2011). The DOS has been validated in a palliative care inpatient setting (Detroyer *et al.* 2014), the Nu-DESC and the SQiD in oncology, and the RADAR in geriatric inpatient and long-term care. The Confusion Assessment Method (CAM) (Inouye *et al.* 1990) is the most recommended delirium screening/ascertainment tool, but takes around 5–10 minutes to complete and requires formal cognitive assessment of the patient, and sufficient user training to ensure adequate sensitivity. These requirements are barriers to its routine use by bedside nurses caring for palliative care patients. However, brief, observational or family versions of the CAM may be feasible for use in this setting (Rao *et al.* 2011, Steis *et al.* 2012, Han *et al.* 2013).

### Study context

This study addresses the research question: Is the Nu-DESC a feasible delirium screening tool for the inpatient palliative care setting? The Nu-DESC (See Box 1) was chosen because this screening tool had been available to the nurses at the study sites for a three-year period in the course of two other delirium studies (Agar 2010, Hosie 2014). Despite its availability, nurses in these units had not yet adopted the Nu-DESC into their routine clinical practice. Over this period nurses had received intermittent training (didactic and one-on-one teaching) on its application, consistent with the level of information provided during the original validation study undertaken by Gaudreau *et al.* (2005). Nurses were not mandated to use the Nu-DESC within the studies or their clinical practice, but had been encouraged and supported to do so by site investigators and research nurses.

To better understand if the Nu-DESC was a feasible screening tool for routine use in inpatient palliative care, we sought nurses' perceptions of its use.

## Aim

To explore nurse perceptions of the feasibility of integrating the Nu-DESC into practice within the inpatient palliative care setting.

## Methods

### Design

A focus group method was chosen to obtain individual and collective views of nurse participants. It was anticipated that focus groups would promote conversation and interaction between them about their experiences and perceptions of using the Nu-DESC and thereby reveal the extent of diversity of opinion about delirium screening and follow-up care within the palliative care unit.

**Box 1.** The Nursing Delirium Screening Scale (Nu-DESC)

The Nu-DESC is a brief (less than one minute), five-item tool, which incorporates nurses' observation of patient: (1) disorientation; (2) inappropriate behaviour; (3) inappropriate communication; (4) illusions/hallucinations; and (5) psychomotor retardation. Each item is assigned a score of 0–2, according to their presence and intensity throughout each eight-hour shift, giving a maximum score of 10. Inclusion of the psychomotor retardation item targets a feature of hypoactive delirium, the most prevalent subtype in palliative care inpatient populations (Hosie *et al.* 2013). Psychometric properties of the Nu-DESC have been evaluated in at least six studies. Apart from one undertaken within an older postoperative population (Neufeld *et al.* 2013), these studies reported good sensitivities and specificities in haemato-oncology, intensive care, geriatric and postoperative populations, ranging from 85·7–100% and 79–92% respectively (Gaudreau *et al.* 2005, Leung *et al.* 2008, Luetz *et al.* 2010, Radtke *et al.* 2010, Abelha *et al.* 2013). Studies used varying comparators [the CAM, CAM-ICU (Ely *et al.* 2001), Intensive Care Delirium Screening Checklist (ICDSC) (Bergeron *et al.* 2001) and DSM-IV (American Psychiatric Association 2000)]; raters (psychiatrist, physician, nurse or assistant researchers and bedside nurses); and training for the Nu-DESC and other tools. These different patient populations and study processes may account for the somewhat varying results.

### Setting and participants

The study took place in two palliative care units, each situated within subacute hospitals in Sydney, Australia. These units provide multidisciplinary care for patients with a life-limiting illness who require symptom management, respite and/or terminal care. Most patients receiving care in the Australian palliative care inpatient setting are aged over 65 years and have a malignant primary diagnosis (Allingham *et al.* 2013).

All nurses working in the participating units who had used the Nu-DESC were eligible to participate. Unit managers informed nurses of the study the week before the focus groups via usual communication channels; for example email and a flyer on staff notice boards. Immediately prior to the groups the unit manager reminded nursing staff about the study and introduced the focus group facilitator. The facilitator gave verbal and written information about the study to nursing staff, who were given the

opportunity to ask questions and discuss the implications of participation. Nurses who elected to participate provided written consent. Participation was voluntary, with no negative consequences if nurses choose not to participate.

### Data collection

To minimise disruption to nurses' workday and patient care focus groups were designed to be of short duration (<30 minutes). A brief semi-structured question route was developed (Box 2) and integrated into a focus group schedule and field note form. Focus groups were timed to occur immediately after nurses' verbal handover (0730 and 1400), to maximise participation and capture the views of nurses working on all shifts. Four focus groups were held during January–February 2014. There were two facilitators (PM and AH), who separately undertook two focus groups at each site. Twenty-one nurses participated, including registered ($n$ = 16), enrolled ($n$ = 3) and assistant nurses ($n$ = 2). The number of participants in each group ranged from 4–7. Groups had a mean duration of 17·5 minutes (range 15–20). Each was digitally recorded and then transcribed by facilitators. Participants were assigned a unique code ('P$n$'), to distinguish each in the documentation and reporting of this study, and maintain their confidentiality.

University and hospital ethics and governance approvals were obtained prior to study commencement.

### Reflexivity

Facilitators were female registered nurses with clinical experience in critical, aged and palliative care, qualitative research and research co-ordination. Because of their on-site research activities facilitators knew most participants by name and role, as well as by voice on the recordings, but did not have a direct collegial or managerial relationship with any. AH was mindful of the need to maintain integrity to participants' responses during data collection and analysis while simultaneously being immersed in the delirium literature and overall project as a doctoral researcher (Tong *et al.* 2007).

**Box 2.** Focus group question route

1 Can you please tell me your thoughts about using the Nu-DESC to screen patients for delirium symptoms?
2 What are your thoughts about the acceptability of this delirium screening tool?
3 Is routine use (each shift) of the Nu-DESC feasible in this palliative care setting?
4 Did using the Nu-DESC influence your practice?
5 Did using the Nu-DESC influence the care your patients received?
6 Does anyone have any further thoughts or comments?

### Reporting

The 'COREQ: consolidated criteria for reporting qualitative research' guided the reporting of this study (Tong *et al.* 2007).

### Data analysis

For consistency facilitators discussed the planned approach prior to data collection; each used the focus group schedule and field note form to guide discussions and PM discussed her impressions and emailed transcriptions to AH on the day of completion of Site 1 focus groups. Digital recordings were transcribed verbatim. The transcript, field note observations and key messages were used to develop codes, categories and themes inductively using thematic content analysis (Liamputtong 2011), initially by one researcher (AH). No qualitative data analysis software was used; instead, participants' quotes were cut and pasted into a word document table, and through immersion in the data, categories and themes were developed. These were then reflected upon and discussed with a second researcher (JP), resulting in conceptual refinement and development of higher level themes. The research team then together considered and discussed these emerging themes, with further refinement occurring to ensure that reported themes accurately reflected participants' perceptions (Liamputtong 2011).

## Results

Three major themes arose from the data and are described below.

### Delirium screening using the Nu-DESC is feasible, but then what?

Overwhelmingly, participants agreed that the Nu-DESC was a brief and easy to administer tool: 'It takes two seconds to do really' (P8) and simple to use: 'It's simple for me, you just have to tick nil or one or two if there's any presentation at that time.' (P12) Most believed the Nu-DESC was feasible in their unit and they likened it to

existing daily symptom screening processes and checking of vital signs: 'It's like doing obs! I think it's feasible' (P18).

This participant reported that the Nu-DESC had helped them to recognise changes in the patient's condition and intervene for their safety:

> It helps identify people who have delirium, and putting early interventions in. There was a patient over the weekend: he was settled when the shift started, but towards the end of it, he was getting confused, agitated. I recognised that this was happening. . .we put a mattress on the floor, the bedrails down, so he didn't fall. (P11)

The Nu-DESC also supported documentation of their observations of patients' symptoms: 'It provides our assessment down on paper.' (P5).

Yet others were uncertain of the purpose for delirium screening: 'What is the goal of this anyhow? To put them on some medication when you find out that they're delirious?' (P19), or if it had activated them to respond: 'I don't know if I actually did a urine test or anything else' (P7). Consistent with uncertainties and variance in follow-up care participants expressed a need for practice guidance, preferably that which could be easily carried on their person, such as a small laminated card:

> It would be nice to have a checklist. For example: infection, do a urine test, blood sugar, pain, bowels importantly, oxygen saturation, hydration. . . because we can't remember everything. (P9)

It was suggested that better guidance might help nurses to first consider a range of possible interventions for the patient rather than hastily resorting to medication:

> If they score two or more, have you thought/considered this? Rather than throw Haloperidol at them. (P8)

Significantly for follow-up care it appeared none had engaged directly with medical colleagues about the Nu-DESC or discussed the finding of the screening process with the patient's treating doctor: 'I'm not even sure if they did look at it. They might have just glanced at it, but not really approached us to say: "Why did you give this score?"' (P11). Participants also wondered how a nurse-completed delirium tool would impact upon their medical colleague's clinical practice:

> It would be good to know how the doctors would use the screening tool. . . Would the screening tool be used for treatment? Would the doctors' review it? If we were going to use it everyday in our practice. . .what's it going to do, how is it going to be used? (P12)

So while participants perceived the Nu-DESC to be an easy, brief tool for use in their unit and therefore feasible, it did not automatically translate to them feeling confident or having a consistent approach to follow-up delirium care. Participants expressed needing additional help to navigate this complex process, including having readily accessible practice guidance and strategies to better communicate with the treating doctors.

### Nuances, ambiguity and clinical complexity of using the Nu-DESC in palliative care

Although participants perceived the Nu-DESC to be easy and brief, its use highlighted the nuances, ambiguities and complexities of delirium recognition in a palliative context. Participants described a range of practical challenges of using the Nu-DESC in this clinical setting, such as determining the best time to complete the scoring during the shift and if an additional screen was required if there was a later change in the patients' clinical condition: 'If there are changes in the patient, do we have to score it again?' (P16). Concerns were also raised about a perceived disconnect between scoring at the end of the shift and trying to make sense of and respond to patients' symptoms and distress during the shift:

> Using the form at the end of the shift, during the shift we're still addressing the issues as they come along. So whether they're incontinent of urine or restless or need pain relief or something for agitation. . .the form isn't really (guiding action). . . For me, it didn't really correlate yet with practice. (P12)

Participants asked: 'How do you score if they are unresponsive or unconscious?' (P11). They also requested clarification of 'psychomotor retardation', item 5 on the Nu-DESC because of the frequency of palliative patients' diminished function:

> Psychomotor retardation. . .people were putting zero, even if there is a change in their normal function of daily living, whereas I was thinking: 'No, it should be one or two', on my shift anyway. I think there were different perceptions about that question. Because we see so much of that in our patients, don't we? (P12) Others: Yeah, yeah.

Participants expressed the need for: '. . .clarity on how to do the assessment itself. People needed more understanding of how to do this.' (P11)

Participants anticipated seeing medication-induced confusion or drowsiness in their patients and were either uncertain whether these adverse effects counted towards the Nu-DESC score or indicated that they should not:

> Our patients in palliative care can be quite drowsy at certain times, depending on their medications. For example, does the patient respond appropriately, or are they making sense? They may not, but this is because they've had drugs. It's hard to clarify and have an objective score. (P6)

There were other uncertainties about the objectivity of the Nu-DESC:

The problem is, it's a variable. An individual nurse's perception of what they think is the score. You mightn't necessarily come up with the same score in the same situation. Sometimes I find following on from someone else's shift, I wonder about their scores. (P2)

I agree with that. (P3)

Participants were aware of the complexity and impact of patients having co-morbidities, prior cognitive impairment and/or irreversible disease progression. They found that: 'Sometimes it's hard to distinguish as to whether its dementia or delirium' (P6). In this palliative care setting, several debated the value of ongoing delirium screening for all patients: 'Some delirium not treatable. It's disease related, so you can't treat it… what do you do when they are scoring all the time?' (P20). Others argued strongly against the presumption that delirium is inevitable and 'not treatable', as exemplified below:

But for a large proportion, the majority are treatable. Like that gentleman we had on the weekend in room 21, he was wandering, he obviously had delirium that wasn't recognised. (P21)

But he has got vascular dementia. (P18)

Yeah, but he'd changed. He started to wander. (P21)

He's got disease progression. (P20)

Yeah, but he's much more alert on Monday than he was on Saturday. Just because someone's got dementia doesn't mean they don't have delirium. That's why sometimes we don't capture them, if they have a cognitive impairment. (P21)

That's why it is hard to recognise, when it's a delirium…dementia, and then cerebral mets. (P18)

But if it's a change in their normal behaviour, wouldn't you agree it is a change on top of what they've already got? They could be reversed. (P21)

This conversation revealed divergent views about the opportunity for interventions to successfully treat delirium, relieve symptoms and distress, and that under-recognition and/or misattribution of delirium symptoms continue to delay nurses response.

### Implementing structured processes requires firmer foundations

Without a firm foundation of knowledge about delirium and the 'how and why' of structured processes for recognition, there is likely to be a degree of resistance to the routine adoption of a tool such as the Nu-DESC.

Despite training and intermittent use misinterpretation of the purpose of the Nu-DESC was common, with several participants viewing it primarily as a monitoring tool for a suspected or established delirium, which prejudiced their willingness to apply it more broadly: 'Use on a patient who had been identified as possibly having a delirium' (P5) and: 'Not sure about its usefulness as a daily thing for the whole ward. Some people don't need it.' (P7) Blurring of the distinction between screening, severity monitoring, comprehensive assessment and diagnosis similarly resulted in hesitancy to advocate for its routine use, due to concern that a positive screen might wrongly attribute delirium to patients who were not delirious:

We have to be careful not to make assumptions. Their behaviour may have changed because they are incontinent of urine or want a drink of water or they're uncomfortable, in pain… (P12)

Willingness to personally apply the Nu-DESC was influenced by participants' perceptions of their own need of a delirium recognition tool. Most acknowledged their delirium knowledge and practice required support. These participants expressed how the Nu-DESC had increased their overall awareness of delirium, including the hypoactive subtype:

It's made us all more aware of the diagnosis of delirium. I used to think that it was another thing that people got when they are dying, but now I realise that you don't have to get it, it might be from infection or some other cause or a medication…there are different causes that can be fixed. (P7)

You know the one: silent, inactive delirium, the quiet one… I never heard of that delirium. Hypoactive delirium was something new to me. (P9)

Having shorter duration of nursing experience, this participant appreciated a structured tool:

I'm a new grad (graduate), so coming on… the tool made it easy to identify the new (symptoms). (P11)

In contrast, some participants ($n = 4$) expressed that 'good' nurses did not need the Nu-DESC to recognise when patients were delirious: 'Probably a good assessment to have on board, but any nurse worth their salt doesn't actually need that assessment to work that out.' (P2) A combination of pride and great confidence in one's nursing capabilities are potential barriers to implementing the Nu-DESC as a routine screening tool:

Experienced staff, who have had a lot of exposure to delirium, you would have done it routinely. . ..you identify them without the tool. I think senior staff, good staff, do it routinely (as) part of your nursing care. . .you don't need the tool. (P5) Other: I agree

Yet these participants acknowledged its potential value for less experienced nurses and/or to provide a record of changes in patients' status over time:

I suppose in the context now that we move between the wards and that we have different patients, it's a good sequential thing that we can look back on. (P2)

. . .for junior staff and students and new staff, I think it's a good way for them to identify what is delirium. (P5)

## Discussion

This study provided valuable insights into nurse perceptions of the Nu-DESC and delirium practice in inpatient palliative care. It also identified opportunities to strengthen nursing delirium recognition and management practices. This is an important area of enquiry, given the prevalence of delirium in this care setting (Hosie *et al.* 2013). Routine screening is the essential first step of delirium care which nurses are ideally placed to initiate. For this to occur, there is a need for brief, low burden and inclusive delirium screening tools with good psychometric properties that can be readily integrated into existing symptom screening systems and nursing practice. While nurses perceived the Nu-DESC to be easy and brief, similar to other symptom screening and instrumental in raising their awareness of delirium, there were numerous knowledge-related barriers to its adoption. Namely, varying understanding of the screening intention of the Nu-DESC, value of structured delirium recognition processes (even when delirium is not reversible) and interventions required following a positive delirium screen. These knowledge gaps were balanced by nurses' desire for greater guidance in optimal delirium care, which seemed to be a major driver for their willingness to adopt the Nu-DESC into clinical practice, even for those who believed their own experience and skill were sufficient to recognise delirium.

However, enthusiasm for routine implementation of the Nu-DESC was diluted whenever there were misunderstandings of its intended purpose and the difference between screening, assessment and diagnosis. Belief that nursing skill and experience is sufficient to recognise delirium also impacted on readiness to adopt a screening tool into one's own practice. Yet being an experienced and/or knowledgeable nurse in a specialist area of care does not of itself ensure adequate recognition of delirium (Mistarz *et al.* 2011). Nurses who disdain the value of a tool will need to be encouraged and supported while they re-learn their approach to delirium recognition. More newly graduated nurses in contrast were most accepting of the Nu-DESC, suggesting their recent nursing education had instilled that symptom screening and assessment be structured and systematic. It may also have been easier for them to acknowledge their need for learning than those with longer duration of nursing experience. This underscores that improving the delirium recognition and assessment capabilities of nurses will not only be supported through continuing practice development for the existing workforce but also through strengthening the delirium learning content in undergraduate nursing curricula. Enthusiastic nurses of all levels of experience can be supported to act as 'change champions' to promote adoption of delirium screening (Shaw *et al.* 2012). For example, a successful approach to improve delirium recognition in an inpatient trauma unit involved the training of junior nurses to provide their more experienced colleagues with real-time feedback about completion of the CAM (Inouye *et al.* 1990). The intervention was well received, resulted in fewer discrepancies between oral and documented reports of patients' mental status, and increased the number of patients identified as delirious (Waszynski *et al.* 2014).

Nurses requested more tailored guidance for use of the Nu-DESC with palliative care patients. Guidance would address nurses' uncertainty about scoring, particularly of the psychomotor retardation item, when patients are not fully responsive or functioning due to medications or being in the dying phase. The original validation study stipulation of 'unusual' and 'taking into account the patient's medical condition' requires precaution in a palliative population (Gaudreau *et al.* 2005). Nurse perceptions that medication-related drowsiness and/or inappropriate patient response ought not to count towards Nu-DESC scores reflect an underlying belief that these adverse drug effects are normal, acceptable and/or innocuous. Assuming that reduced responsiveness and functioning is always expected for palliative care patients is similar to erroneous attitudes that cognitive impairment is a normal part of ageing (McCarthy 2003). These attitudes are major barriers to delirium recognition and timely management of iatrogenic or reversible precipitants. For instance, delayed responsiveness may herald that a patient is dying, or alternatively, that a frail, older but previously highly functioning patient is experienc-

ing a severe adverse effect of a new analgesic. While these patients may have similar initial presentations and Nu-DESC scores, the underlying cause, significance and management will vary according to each patient's circumstances and are best informed by the outcomes of a full assessment and team consultation.

Nurses in this study reported a disconnect between knowing something was amiss with their patient, wanting to act to relieve patient distress, and assigning a Nu-DESC score at the end of a shift, indicating that definitive and immediate delirium confirmation strategies may be required to augment the Nu-DESC. For example the conjoint use of a dichotomous tool, such as an observational version of the CAM. Point-of-care access to the DSM-5 delirium diagnostic criteria may also support nurses and teams to more accurately and confidently interpret a positive Nu-DESC screen and take immediate positive action.

Nurses revealed varying responses to a positive delirium screen, including: no action, instigating team discussion of observed changes and putting safety measures in place, and instigation of pharmacological interventions before nonpharmacological interventions were trialled. This last approach was disquieting because of possible missed iatrogenic or reversible causes and insufficient evidence for any class of medication for delirium in this population (Bush *et al*. 2014). Nurses apprehended that screening is only one step in delirium care and they wanted readily accessible guidance for the follow-up care of patients with a positive Nu-DESC. This urges the building and integration of delirium evidence in this care setting (Lawlor *et al*. 2014).

In palliative care, teamwork is essential; yet here, as elsewhere, a united approach to delirium care by nurses and doctors was missing (Kjorven *et al*. 2011, Al-Qadheeb *et al*. 2013, Hosie *et al*. 2014). Nurses were uncertain if doctors had noticed Nu-DESC scores and/or what action they would take for a positive delirium screen, and they wanted to be assured of their involvement. Of note, none mentioned how good interdisciplinary teamwork required nurses to take responsibility to alert doctors to changes in the patients' status. This finding may reflect that these nurses' had perceived that the primary purpose of using the Nu-DESC was for research purposes and therefore they had not thought it necessary to take any clinical ownership of delirium screening within their units. As suboptimal team communication about delirium is a re-occurring theme within the literature (Kjorven *et al*. 2011, Al-Qadheeb *et al*. 2013, Hosie *et al*. 2014), purposeful interdisciplinary communication and collaboration will be key to the success of future knowledge translation initiatives, in which nurses must take an active role.

## Strengths and limitations

The limitations of this study include the convenience sample. Participants worked within two metropolitan Australian palliative care units and findings may not be transferable to other care settings. Due to timing and funding constraints, only four focus groups were conducted. Although there was consistency in participants' responses, we did not continue data collection with the express intent of confirming data saturation and confirmation of themes. No data were collected on participants' duration of palliative care experience or Nu-DESC usage. Nurses had furthermore only used the Nu-DESC intermittently, with potential for further insights had there been greater regularity of use. However, obtaining these nurses' perceptions was important in guiding on-site knowledge translation and provides valuable information for future delirium recognition interventions in palliative care. The strength of this study is the inclusion of nurses' voices about an aspect of delirium care for which they are responsible and can make a positive contribution towards.

## Conclusion

Nurses working in two Australian palliative care units perceived the Nu-DESC to be an easy and brief delirium screening tool which raised their awareness of delirium and which they were largely willing to adopt into practice. Investigation of the further psychometric properties of the Nu-DESC and other delirium tools in the palliative care setting is required, prior to advocating for routine use.

## Relevance to clinical practice

Ensuring early recognition of delirium and optimal follow-up care for patients should be a priority in inpatient palliative care. Successful implementation and effective delirium screening in this setting will require not only the use of a feasible and validated tool but also a multifaceted approach that includes nurse education and the tailoring of tools and guidance to the context. Palliative care nurses must furthermore become more active leaders and collaborators within their interdisciplinary teams for effective delirium practice change to be achieved.

## Acknowledgements

The authors acknowledge the contributions of the nurses who participated in this study, the support of their managers and Ms Paula Mohacsi for her assistance with the facilitation and transcription of the focus groups. An Australian Postgraduate Award from the Commonwealth Government of Australia supported the first author in this work.

## Contributions

AH, EL, MA, PD, RC and JP each contributed to the study design. AH was responsible for data collection, initial data analysis and drafting of the manuscript. EL, MA, PD, RC and JP each contributed to analysis and interpretation of data, revision of the manuscript and approval of the final version.

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# APPENDIX 3

# *DATA COLLECTION TOOLS*

**Sub-study 1** **Baseline organisational questionnaire** **V1 April 2013**

| Item | | P=Present NP=Not Present | Rate the degree to which the statement is true of your service 0= Not at all 10 = Fully implemented and effective | Rate priority for future action 0= Not at all – no action required 10= Undertake as a matter of urgency |
|---|---|---|---|---|
| | **Section 1: Policy and Procedure** | | | |
| | The unit has a policy or protocol related to delirium care of patients | | | |
| | Policy or protocols includes requirements for delirium screening of patients | | | |
| | Policy or protocols includes instructions/guidance for comprehensive delirium assessment of patients | | | |
| | Policy or protocols references current delirium clinical practice guidelines (indicate below) | | | |
| | □Clinical Practice Guidelines for the Management of Delirium in Older People, Clinical Epidemiology and Health Service Evaluation Unit, Melbourne Health, 2006<br>□ Guideline on the Assessment and Treatment of Delirium in Older Adults at the End of Life, Canadian Coalition for Seniors' Mental Health, 2010<br>□ NIHCE Delirium Guidelines, NHS National Institute for Health and Clinical Evidence, 2010<br>□ Therapeutic Guidelines for Palliative Care<br>□ Other | | | |
| | **Section 2: Screening and assessment tools** | | | |
| | There is a validated delirium-screening tool available for use (indicate below) | | | |
| | □ Confusion Rating Scale (CRS)<br>□ Confusion Assessment Method (CAM)<br>□ Bedside Confusion Scale (BCS)<br>□ Nursing Delirium Screening Scale (NuDESC)<br>□ Delirium Observation Screening Scale (DOS)<br>□ Other | | | |
| | A validated delirium assessment tool is available for use (indicate below) | | | |
| | □Delirium Rating Scale (DRS)<br>□ Delirium Rating Scale-Revised-98 (DRS-R-98)<br>□ Memorial Delirium Assessment Scale (MDAS)<br>□ Delirium Index (DI)<br>□ NEECHAM Confusion Scale<br>□ Other | | | |
| | There is a cognition assessment tool available (indicate below) | | | |
| | □ MMSE<br>□ Clockface Drawing Test<br>□ Other | | | |

Sub-study 1 Baseline organisational questionnaire V1 April 2013

| Item | | P=Present NP=Not Present | Rate the degree to which the statement is true of your service 0= Not at all 10 = Fully implemented and effective | Rate priority for future action 0= Not at all – no action required 10= Undertake as a matter of urgency |
|---|---|---|---|---|
| | **Section 3: Quality Improvement and Research Projects** | | | |
| | The unit has a current quality improvement programme related to delirium (indicate below) | | | |
| | □ Delirium prevention<br>□ Delirium screening<br>□ Delirium assessment<br>□ Pharmacological treatment<br>□ Non-pharmacological treatment<br>□ Patient support<br>□ Family support<br>□ Other | | | |
| | The unit has research project/s related to delirium currently in progress (indicate below) | | | |
| | □ Delirium prevention<br>□ Delirium screening<br>□ Delirium assessment<br>□ Pharmacological treatment<br>□ Non-pharmacological treatment<br>□ Patient support<br>□ Family support<br>□ Other | | | |
| | **Section 4: Admission and discharge processes** | | | |
| | Admission processes include screening or assessment of delirium symptoms | | | |
| | Discharge processes include screening or assessment of delirium symptoms | | | |
| | **Section 5: Delirium prevalence as a Key Performance Indicator** | | | |
| | Delirium occurrence is one of the unit's key performance indicators | | | |
| | Data on the occurrence of delirium in the unit is routinely collected (Describe) | | | |
| | Patient response to delirium intervention is one of the unit's key performance indicators | | | |
| | Data on patient response to delirium intervention is routinely collected (Describe) | | | |

Delirium point prevalence audit – Audit Tool Participant Code

**Patient Delirium Symptom Audit**

**Part A: Patient Demographic, Diagnostic and Functional Details**

1. Age

2. Gender: Male ☐ Female ☐

3. Number of days since admission……

4. Indigenous Status

☐ Aboriginal but not Torres Strait Islander origin ☐ Torres Strait Islander but not Aboriginal origin

☐ Both Aboriginal and Torres Strait Islander origin ☐ Neither Aboriginal nor Torres Strait Islander

☐ Not stated / inadequately described

5. Country of Birth ☐ Australia ☐ Other, specify

6. Preferred language ☐ English ☐ Other, specify

7. Postcode of place of residence……

8. Primary Diagnosis (principal life limiting illness)

Malignant

☐ Bone & soft tissue ☐ Gynaecological ☐ Pancreas ☐ Other GIT

☐ Breast ☐ Haematological ☐ Prostate ☐ Other Urological

☐ CNS ☐ Head and Neck ☐ Skin ☐ Other Malignancy

☐ Colorectal ☐ Lung ☐ Unknown Primary

Non-malignant

☐ Cardiovascular disease ☐ Alzheimer's disease ☐ Diabetes & its complications

☐ HIV/AIDS ☐ Other dementia ☐ Sepsis

☐ End stage kidney disease ☐ Other neurological disease ☐ Multiple organ failure

☐ Stroke ☐ Respiratory failure ☐ Other non malignancy

☐ Motor Neurone Disease ☐ End stage liver disease

9. Palliative care phase and patient function

| | 0700-1500 | 1500-2300 | 2300-0700 |
|---|---|---|---|
| Palliative care phase (1-5) | | | |
| RUG-ADL (4-18) | | | |
| AKPS (10-100) | | | |

Audit date Date of completion 1

Person completing (Initials)

Delirium point prevalence audit – Audit Tool Participant Code

**Part B: Delirium Screening (NuDESC)**

| FEATURES AND DESCRIPTIONS | SYMPTOM RATING 0 - 2 | | |
|---|---|---|---|
| Symptom/Time period | 1400<br>Day Shift | 2200<br>Evening Shift | 0600<br>Night Shift |
| DISORIENTATION:<br>Verbal or behavioural of not being orientated to time or place or misperceiving persons in the environment | | | |
| INAPPROPRIATE BEHAVIOUR:<br>Behaviour inappropriate to place and/or for the person e.g. pulling at tubes or dressings, attempting to get out of bed when that is contraindicated and the like | | | |
| INAPPROPRIATE COMMUNICATION:<br>Communication inappropriate to place and/or for the person e.g. incoherence, non-communicativeness, nonsensical or unintelligible speech | | | |
| ILLUSIONS/HALLUCINATIONS:<br>Seeing or hearing things that are not there, distortion of visual objects | | | |
| PSYCHOMOTOR RETARDATION:<br>Delayed responsiveness, few or no spontaneous actions/words e.g. when patient is prodded, reaction is deferred and/or the patient is unrousable | | | |
| Total score (out of 10) | | | |

If score is ≥2, inform treating medical team so that further delirium assessment using the MDAS, investigation and treatment is implemented.

Time taken for nurse to complete NuDESC:_____

Reasons for non-completion of NuDESC?

_____

_____

_____

_____

Audit date Date of completion 2

Person completing (Initials)

Delirium point prevalence audit – Audit Tool Participant Code

**Part C: Delirium Assessment (MDAS)**

Verbal consent of patient obtained Yes ☐ No ☐

If 'Yes' to both, complete MDAS

| MDAS ITEM | Score |
|---|---|
| ITEM 1 - Reduced level of consciousness (awareness) | |
| ITEM 2 - Disorientation | |
| ITEM 3 - Short term memory impairment | |
| ITEM 4 - Impaired digit span | |
| ITEM 5 - Reduced ability to maintain and shift attention | |
| ITEM 6 - Disorganised thinking | |
| ITEM 7 - Perceptual disturbance | |
| ITEM 8 - Delusions | |
| ITEM 9 - Decreased or increased psychomotor activity | |
| Identify type of psychomotor activity:<br>(a) Hypoactive<br>(b) Hyperactive<br>(c) Elements of both present | |
| ITEM 10 – Sleep-wake cycle disturbance (disorder of arousal) | |

All items on MDAS completed? Yes ☐ No ☐

If 'No', tick reason/s for non-completion:

Patient refusal ☐ Family refusal ☐ Patient unable ☐ Other ☐ _____

Time taken for medical officer to complete MDAS:_____

Document any other observations made during MDAS:

_____

_____

_____

_____

Audit date Date of completion 3

Person completing (Initials)

Delirium point prevalence audit – Audit Tool Participant Code

**Part D: Delirium Diagnostic Criteria (DSM-5)**

The patient has:

A. Disturbed attention (i.e. reduced ability to focus, sustain or shift attention) and awareness (reduced orientation to the environment) ☐

B. Disturbance developed over a short period of time (usually hours to a few days), represents a change from baseline attention and awareness, and tends to fluctuate in severity during the course of the day ☐

C. An additional disturbance in cognition e.g. (memory deficit, disorientation, language, visuospatial ability, or perception) ☐

D. The disturbances in Criteria A and C are not better explained by another pre-existing, established, or evolving neurocognitive disorder and do not occur in the context of a severely reduced level of arousal, such as coma ☐

E. Evidence from the history, physical examination, or laboratory findings that the disturbance is a direct physiological consequence of another medical condition, substance intoxication or withdrawal (i.e. due to a drug of abuse or to a medication), or exposure to a toxin, or is due to multiple etiologies ☐

Name: Signature:

Audit date Date of completion 4

Person completing (Initials)

***Determining the feasibility and acceptability of delirium screening using the NuDESC in specialist palliative care inpatient units***

Focus Group interviewer notes:

Date: /01/2014

FG #: _____

- Used NuDESC in Nov-Dec 2013 used
- 3/12 mths at Sacred Heart

**Focus group questions**

1. Can you please tell me your thoughts about using the NuDESC to screen patients' for delirium symptoms?

2. What are your thoughts about the acceptability of this delirium screening tool?

3. Is routine use (each shift) of the NuDESC feasible in this palliative care setting?

4. Did using the NuDESC influence your practice?

5. Did using the NuDESC influence the care your patients received?

# APPENDIX 4

# *HREC APPROVALS*

THE UNIVERSITY OF NOTRE DAME AUSTRALIA

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ABN: 69 330 643 210
CRICOS PROVIDER CODE: 01032F

13 August 2012

Professor Jane Phillips
School of Nursing
The University of Notre Dame Australia
Sydney Campus

Reference Number: 012058S

Dear Jane,

I am writing to you in regards to your Low Risk Application for Ethics Clearance for your proposed research, to be undertaken as a student project at The University of Notre Dame Australia.The title of the project is: *"Exploring nurses' capabilities and practices in recognising acute changes in patients' awareness cognition and perception in specialist palliative care inpatient units, through Critical Incident Technique."*

Your proposal has been reviewed by the University's Human Research Ethics Committee, and based on the information provided has been assessed as meeting all the requirements as mentioned in the *National Statement on Ethical Conduct in Human Research* (2007). I am therefore pleased to advise that ethical clearance has been granted for this proposed study.

***All research projects are approved subject to standard conditions of approval. Please read the attached document for details of these conditions.***

On behalf of the Human Research Ethics Committee, I wish you well with what promises to be a most interesting and valuable study.

Yours sincerely,

Dr Natalie Giles
Executive Officer, Human Research Ethics Committee
Research Office

cc: Dr Tracey Thornley, Dean, School of Nursing Sydney.

# St Vincent's Hospital

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4 December 2012

Prof Jane Phillips
Cunningham Centre
PO Box
Broadway NSW 2007

Dear Jane

**SVH File Number: 12/227**
**Project Title: Exploring nurses' capabilities and practices in recognising acute changes in patients' awareness, cognition and perception in specialist palliative care inpatient units, through Critical Incident Technique. (HREC Reference Number: LNR/12/SVH/336)**

Thank you for submitting the above project for review. Based on the information you have provided and in accordance with the NHMRC National Statement 2007 and NSW Health Policy Directive PD2010_055 Ethical and Scientific Review of Human Research in NSW Public Health Organisations, this project has been assessed as low/negligible risk and is therefore exempt from full HREC review.

This HREC has been accredited by NSW Ministry of Health as a Lead HREC under the model for single ethical and scientific review and Certified by the NHMRC under the National model for Harmonisation of Multicentre Ethical Review (HoMER).This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. No HREC members with a conflict of interest were present for review of this project.

I am pleased to advise that the HREC Executive at a meeting on **4 December 2012** has granted ethical and scientific approval of the above **multi centre** project.

**You are reminded that this letter constitutes *ETHICAL* and *SCIENTIFIC* approval only. You must not commence this research project at a site until a completed Site Specific Assessment Form and associated documentation have been submitted to the site Research Governance Officer and Authorised. A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.**

The project is approved to be conducted at the following sites:

- Braeside Hospital
- St Joseph's Hospital
- Lourdes Hospital, Dubbo

If a new site(s) is to be added please inform the HREC in writing and submit a Site Specific Assessment Form (SSA) to the Research Governance Officer at the new site.

The following documents have been approved:

- Protocol Version 1.5 dated October 2012
- Participant Information Sheet and Consent Form Version 1 dated 9 November 2012

The Low and Negligible Risk Research Form (LNRF) reviewed by the HREC was LNRF **AU/6/D2EF04**.

Please note the following conditions of approval:

- HREC approval is valid for **5 years** from the date of the HREC Executive Committee meeting and expires on **4 December 2017**. The Co-ordinating Investigator is required to notify the HREC 6 months prior to this date if the project is expected to extend beyond the original approval date at which time the HREC will advise of the requirements for ongoing approval of the study.

- The Co-ordinating Investigator will provide an annual progress report beginning in **December 2013**, to the HREC as well as a final study report at the completion of the project in the specified format.

- The Co-ordinating Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project and any complaints made by participants regarding the conduct of the project.

- Proposed changes to the research protocol, conduct of the research, or length of approval will be provided to the HREC Executive for review, in the specified format.

- The HREC Executive will be notified, giving reasons, if the project is discontinued before the expected date of completion.

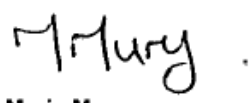
- Projects that are undertaken by Investigators holding an academic appointment (including conjoint appointments) or by students as part of a University course are also required to notify the relevant University HREC.

Should you have any queries about your project please contact the Research Office, Tel: 8382-2075, email research@stvincents.com.au. The HREC Terms of Reference, Standard Operating Procedures, *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice* and standard forms are available on the Research Office website: www.stvincents.com.au/researchoffice or internal at http://exwwwsvh.stvincents.com.au/researchoffice

Please quote **SVH File Number 12/227** in all correspondence.

The HREC wishes you every success in your research.

Yours sincerely



**Maria Mury**
**Acting HREC Executive Officer**
**Research Office**
L6 deLacy Building

CC: Annmarie Hosie
Trim File Ref:D/2012/55003

# St Vincent's Hospital

A facility of St Vincents
& Mater Health Sydney

St Vincent's Hospital Sydney Ltd
ABN 77 054 038 872
390 Victoria Street
Darlinghurst NSW 2010
Australia

T + 61 2 8382 1111
F + 61 2 9332 4142
www.stvincents.com.au

27 June 2013

A/Professor Richard Chye
Palliative Care Services
Sacred Heart
Darlinghurst NSW 2010

Dear Richard

**SVH File Number: 13/101**
**Project Title: Screening and assessment of delirium symptoms in specialist palliative care inpatient units - The DePAC Study - Numbers 1, 2 & 3**
**(HREC Reference Number: HREC/13/SVH/152)**

Thank you for submitting the above project for ethical and scientific review. The project was first considered by the St Vincent's Hospital HREC at its meeting held on **9 May 2013.** This HREC has been accredited by NSW Ministry of Health as a Lead HREC under the model for single ethical and scientific review and Certified by the NHMRC under the National model for Harmonisation of Multicentre Ethical Review (HoMER). This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. No HREC members with a conflict of interest were present for review of this project.

I am pleased to advise that the Committee at an Executive meeting on **25 June 2013** has granted ethical and scientific approval of the above **multi centre** project.

**You are reminded that this letter constitutes *ETHICAL* and *SCIENTIFIC* approval only. You must not commence this research project at a site until a completed Site Specific Assessment Form/Access Request and associated documentation have been submitted to the site Research Governance Officer and Authorised. A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.**

The project is approved to be conducted at:

- **St Vincent's Hospital Sydney**
- **Braeside Palliative Care Unit**
- **Calvary Health Care Sydney**

If a new site(s) is to be added please inform the HREC in writing and submit a Site Specific Assessment Form (SSA) to the Research Governance Officer at the new site.

The following documentation has been reviewed and approved by the HREC:

- Protocol (including appendices) Version 1.1 dated June 2013
- Patient Information Sheet and Consent Form – Baseline Questionnaire, Version 1.1 dated June 2013
- Patient Information Sheet and Consent Form – Focus Group, Version 1.1 dated June 2013
- Advertisement Poster, Version 2 dated June 2013

The National Ethics Application Form (NEAF) document reviewed by the HREC was NEAF **AU/1/984215.**

Please note the following conditions of approval:

- HREC approval is valid for **5 years** from the date of the HREC Executive Committee meeting and expires on **25 June 2018.** The Co-ordinating Investigator is required to notify the HREC 6 months prior to this date if the project is expected to extend beyond the original approval date at which time the HREC will advise of the requirements for ongoing approval of the study.

- The Co-ordinating Investigator will provide an annual progress report beginning in **June 2014**, to the HREC as well as a final study report at the completion of the project in the specified format.

- The Co-ordinating Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project and any complaints made by study participants regarding the conduct of the study.

- Proposed changes to the research protocol, conduct of the research, or length of HREC approval will be provided to the HREC for review, in the specified format.

- The HREC will be notified, giving reasons, if the project is discontinued before the expected date of completion.

- Investigators holding an academic appointment (including conjoint appointments) and students undertaking a project as part of a University course may also be required to notify the relevant University HREC of the project. Investigators and students are advised to contact the relevant HREC to seek advice regarding their requirements.

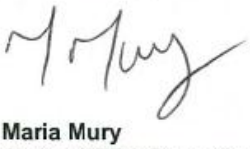
Please note it is the responsibility of the sponsor or the co-ordinating investigator of the project to register this study on a publicly available online registry (eg Australian Clinical Trial Registry www.actr.org.au ).

Should you have any queries about your project please contact the Research Office, Tel: 8382-2075, email research@stvincents.com.au. The HREC Terms of Reference, Standard Operating Procedures, *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice* and standard forms are available on the Research Office website: www.stvincents.com.au/researchoffice or internal at http://exwwwsvh.stvincents.com.au/researchoffice

Please quote **SVH File Number: 13/101** in all correspondence.

The HREC wishes you every success in your research.

Yours sincerely



**Maria Mury**
**Acting HREC Executive Officer**
**Research Office**
L6 deLacy Building

CC: Annmarie Hosie
Filename: D/2013/35089

THE UNIVERSITY OF NOTRE DAME AUSTRALIA

19 Mouat Street (PO Box 1225)
Fremantle, Western Australia 6959
Telephone: +61 8 9433 0555
Facsimile: +61 8 9433 0544
Email: enquiries@nd.edu.au
Internet: www.nd.edu.au

ABN: 69 330 643 210
CRICOS PROVIDER CODE: 01032F

16 July 2013

Professor Jane Phillips
School of Nursing
The University of Notre Dame, Australia
Sydney Campus

Dear Jane,

**Reference Number: 013111S**

**Project title: "Screening and assessment of delirium symptoms in specialist palliative care inpatient units - The DePAC Study."**

Thank you for submitting the above project for review. Based on the information you have provided and in accordance with the *National Statement on Ethical Conduct in Human Research* (2007), this project has been assessed as qualifying for a Cross-Institutional approval and is therefore exempt from HREC review. I am pleased to advise that ethical clearance has been granted for this proposed study.

**All research projects are approved subject to standard conditions of approval. Please read the attached document for details of these conditions.**

Should you have any queries about this project, please contact me at #2964 or Natalie.Giles@nd.edu.au.

Yours sincerely,

Dr Natalie Giles
Executive Officer, Human Research Ethics Committee
Research Office

cc: Dr Tracey Thornley, Dean, School of Nursing Sydney

# APPENDIX 5

# *STUDY INFORMATION AND CONSENT DOCUMENTS*

# Participant Information Sheet and Consent Form
# Non-interventional Research

| | |
|---|---|
| **Title** | ***Baseline questionnaire of organisational capacity to screen and assess delirium*** |
| **Principal Investigators** | **Associate Professor Richard Chye**<br>**Professor Jane Phillips**<br>**Associate Professor Meera Agar**<br>**Professor Liz Lobb**<br>**Ms Annmarie Hosie** |
| **Site** | **Braeside/Sacred Heart/Calvary Health Care Sydney (only relevant site name will be inserted)** |
| **Protocol** | **V1.1** |

## Part I – What does my participation in the study involve?

### 1 Introduction

You are invited to take part in a questionnaire about delirium screening and assessment. This Participant Information Sheet and Consent Form tells you about the study. It explains what is involved to help you decide if you want to take part in the study. Please read this information carefully. Ask questions about anything that you do not understand or want to know more about. Before deciding whether or not to take part you might want to talk about it with a manager, colleague or another trusted person.

### 2 What is the purpose of this research?

The aim of this questionnaire is to identify and describe the existing organisational capacity within a set of inpatient palliative care services in Sydney, to screen and assess delirium. Although delirium is prevalent in palliative care inpatient settings, delirium screening and assessment may not be routinely integrated into systems and processes of care, which may contribute to under-recognition of this distressing syndrome. It is hoped that this study will better describe the practice context and help identify any gaps in systems and/or processes in delirium care at participating palliative care sites. This questionnaire is being conducted in conjunction with two other delirium studies to be implemented at your site and will be completed at baseline i.e. prior to the two other studies.

### 3 Why have I been chosen?

You are being invited to participate in this questionnaire because you have been identified by the study site investigator/s as being employed in a key role within your unit and have worked at your unit for more than three months.

**4 Do I have to take part in the research?**

It is up to you to decide whether or not to take part in this study. If you do decide to take part you will be given this Participant Information Sheet and Consent Form to sign and you will be given a copy to keep. If you decide to take part you can change your mind later and withdraw from the study prior to the completion of the questionnaire, for any reason.

**5 Other relevant information (i.e. size of project, number of participants, organisations)**

This study involves researchers from a number of different palliative care services and the University of Notre Dame working in collaboration. It is anticipated that up to four specialist palliative care units in Sydney, Australia will take part in this study. The number of participants at your site involved in the completion of this questionnaire may range from 3-8 key personnel.

**6 What will happen to me if I take part and what do I have to do?**

If you agree to participate in this study, you will be asked to sign the Participant Consent Form and give some information about your role and length of time you have worked at the unit. You will then be asked to participate in a group discussion with other participating colleagues and investigator Ms Hosie.

The purpose of the group discussion is to complete a face-to-face questionnaire about the degree of implementation of delirium screening and assessment policy, procedures, processes, tools, key performance indicators and quality or research projects underway at your unit and the degree of priority for future action. Ms Hosie will be responsible for completing each questionnaire item, using information from the group discussion. A consensus approach will be used to determine the answer to each item.

It is anticipated that this discussion and completion of the questionnaire will take no longer than one hour and will be held on-site in a suitable meeting room and a time determined to be the most suitable for participants.

There are no costs associated with participating in this study, nor will you be paid. You will be not be reimbursed for any costs that you incur as a result of participating in this study, such as travel to attend the meeting. Refreshments will be provided during the group discussion.

**7 What are the possible benefits of taking part?**

We cannot guarantee or promise that you will receive any benefits from this research, however a possible benefit might be enjoyment of the opportunity to be involved in the development of knowledge about delirium practice in palliative care inpatient settings.

**8 What are the risks of taking part?**

There is a risk that participation in the completion of the questionnaire will cause you inconvenience and/or add to your workload. There is also a risk that you may find it challenging to examine the current delirium systems and practices within your unit.

**9 What do I do if I wish to withdraw from the research?**

Participation in any research project is voluntary. If you do not wish to take part you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project prior to the completion of the questionnaire. If you wish to withdraw from this study please advise investigator Ms Hosie.

If you do withdraw you will be asked to complete and sign a "Withdrawal of Consent' form, which is contained within this participant information sheet and consent form.

**10 What happens when the study ends?**

The results of the questionnaire will be made available to each unit and all participants, once available.

## Part II – How is the study being conducted?

**11 What will happen to information about me?**

By signing the consent form, you consent to the study coordinator and relevant research staff collecting and using personal information about you for the study project. Any information obtained in connection with this study that can identify you will remain confidential. Your personal information will be kept securely in a locked cupboard in a locked office at The Cunningham Centre for Palliative Care at the Sacred Heart Palliative Care Service, Darlinghurst and on password protected computers accessible only by study investigators. Your information will only be used for the purpose of this study and it will only be disclosed with your permission, except as required by law.

The personal information we will collect and use for this study is your name, role, site of work and length of time employed there. This information will be kept securely for a period of five years from the date of any publications arising from this study. After this time this information will be permanently destroyed.

It is anticipated that the results of this study will be published and or presented in a variety of forums. In any publication and/or presentation, all information will be provided in such a way that you cannot be identified, nor will your site's individual results be linked to your sites name. Sites will be identified as Site A, Site B, etc.

In accordance with relevant Australian and/or NSW privacy and other relevant laws, you have the right to request access the information collected and stored by the study team about you. You also have the right to request that any information with which you disagree be corrected. Please contact the study team member named at the end of this document if you would like to access your information.

**12 What if something goes wrong?**

If you suffer any distress or psychological injury as a result of this study, you should contact the study team as soon as possible, who will assist you in arranging appropriate treatment and support.

**13 Who is organising and funding the research?**

The study is being conducted by:

- Associate Professor Richard Chye, The Cunningham Centre for Palliative Care and Sacred Heart Palliative Care Service

- Professor Jane Phillips, The University of Notre Dame Australia, Sydney and The Cunningham Centre for Palliative Care
- Associate Professor Meera Agar, University of NSW and Medical Director of the Braeside Palliative Care Service
- Professor Liz Lobb, Calvary Health Care Sydney and The Cunningham Centre for Palliative Care
- Ms Annmarie Hosie, School of Nursing, University of Notre Dame, Sydney
- Associate Investigator (name)

The study is being undertaken as one component of investigator Ms Hosie's doctoral research at The University of Notre Dame, Sydney.

No investigator or member of research staff will receive a personal financial benefit from your involvement in this study.

**14 Who has reviewed the study?**

All research in Australia involving humans is reviewed by an independent group of people, called a Human Research Ethics Committee (HREC). This study has been reviewed and given approval by St Vincent's Hospital (Sydney) Human Research Ethics Committee.

The conduct of this study at <<insert name of site>>has been authorised by the <<insert name of organisation>>.

**15 Further information and who to contact**

If you would like any further information on this study you may contact Ms Annmarie Hosie on 0417292077.

If you would like to talk to someone not directly involved with the study for any further information regarding your rights as a study participant or should you wish to make a complaint to people independent of the study team, you may contact the St Vincent's Hospital (Sydney) Reserach Office on (02) 8382 2075 and quote the HREC reference number: HREC/13/SVH/152.

| Question | Who to contact | Phone / Facsimile |
|---|---|---|
| General questions or concerns during the study | Study Coordinator Ms Annmarie Hosie<br><br>Principal Investigator (for site) | Phone 0417 292 077<br>Facsimile + 61 2 8382 9518<br><br>Phone<br>Facsimile |
| Questions about the way the research is being conducted | HREC Executive Officer<br><br>Institutional Research Governance Officer | Phone +61 2 8382 2075<br>Facsimile +61 2 9332 4142<br><br>Phone<br>Facsimile |

THE UNIVERSITY OF NOTRE DAME AUSTRALIA

**PARTICIPANT CONSENT FORM**

| | |
|---|---|
| **Title** | ***Baseline questionnaire of organisational capacity to screen and assess delirium*** |
| **Principal Investigators** | **Associate Professor Richard Chye**<br>**Professor Jane Phillips**<br>**Associate Professor Meera Agar**<br>**Professor Liz Lobb**<br>**Ms Annmarie Hosie** |
| **Site** | **Braeside/Sacred Heart/Calvary Health Care Sydney (only relevant site name will be inserted)** |
| **Protocol** | **V1** |

1. I have read the attached Participant Information Sheet outlining the nature and purpose of the research study and I understand what I am being asked to do.
2. I have discussed my participation in this study with the member of the study team named below. I have had the opportunity to ask questions and I am satisfied with the answers I have received.
3. I have been informed about the possible risks of taking part in this study.
4. I freely consent to participate in the research project as described in the attached Participant Information Sheet.
5. I understand that my participation is voluntary and that I am free to withdraw at any time during the study.

| Name of Participant | Signature of Participant | Date |
|---|---|---|
| Name of Witness to Participant's Signature | Signature of Witness | Date |

*Witness is not to be the Investigator or member of the study team nor their delegate
* Please note that in the event that an Interpreter is used, the Interpreter is not a witness to the consent process

| Name of Investigator | Signature of Investigator | Date |
|---|---|---|

*Participant will be provided with a copy of the Participant Information Sheet and this Consent Form*
*All parties signing the Consent Form must date their own signature*

THE UNIVERSITY OF NOTRE DAME AUSTRALIA

***WITHDRAWAL OF PARTICIPATION***

| | |
|---|---|
| **Title** | ***Baseline questionnaire of organisational capacity to screen and assess delirium*** |
| **Principal Investigators** | **Associate Professor Richard Chye**<br>**Professor Jane Phillips**<br>**Associate Professor Meera Agar**<br>**Professor Liz Lobb**<br>**Ms Annmarie Hosie** |
| **Site** | **Braeside/Sacred Heart/Calvary Health Care Sydney (only relevant site name will be inserted)** |
| **Protocol** | **V1** |

I hereby wish to WITHDRAW my intent to participate further in the above research project and understand that such withdrawal will not jeopardise my future professional relationships with the study investigators.

Participant's Name (printed) _____.

Signature _____.

Date _____.

In the event the participant decided to withdraw verbally, please give a description of the circumstances. Coordinating Investigator to provide further information here:

| |
|---|
| |

Coordinating Investigator to sign the withdrawal of consent form on behalf of a participant if verbal withdrawal has been given:

Participant's Name (printed) _____.

Signature of Investigator _____.

Date _____.

*Participant will be provided with a copy of this Withdrawal of Consent Form*

THE UNIVERSITY OF NOTRE DAME AUSTRALIA

Site

# Information for Patients and Families

[Name of site] is currently participating in a study investigating ways to better measure the burden of delirium symptoms in the palliative care setting.

As part of their normal care, nurses record their observations of patients regularly. If a patient shows signs of delirium during these observations, the nurse notifies a doctor.

You may notice the doctors asking patients who are delirious some brief questions to assess memory, attention and orientation. The doctors will only ask these questions if the patient is willing and able to answer.

If you have any questions about this study or would like more information, please talk with the staff or the Principal Investigator at [site]...[name].

This study has been approved by St Vincent's Hospital HREC, HREC/13/SVH/152
DePAC Study No 2 - Patient and family information poster v2 June 2013

THE UNIVERSITY OF NOTRE DAME AUSTRALIA

**Participant Information Sheet and Consent Form**
**Non-interventional Research**

| | |
|---|---|
| **Title** | ***Determining the feasibility and acceptability of delirium screening and assessment processes in specialist palliative care units*** |
| **Principal Investigators** | **Associate Professor Richard Chye**<br>**Professor Jane Phillips**<br>**Associate Professor Meera Agar**<br>**Professor Liz Lobb**<br>**Ms Annmarie Hosie**<br>**Site Investigator (name)** |
| **Site** | **Braeside/Sacred Heart/Calvary Health Care Sydney (only relevant site name will be inserted)** |
| **Protocol** | **V1.1** |

## Part I – What does my participation in the study involve?

### 1 Introduction

You are invited to take part in a focus group exploring your perceptions of the feasibility and acceptability of delirium screening and assessment in specialist palliative care inpatient units. This Participant Information Sheet and Consent Form tells you about the study. It explains what is involved to help you decide if you want to take part in the study. Please read this information carefully. Ask questions about anything that you do not understand or want to know more about. Before deciding whether or not to take part you might want to talk about it with a manager, colleague or another trusted person.

### 2 What is the purpose of this research?

This focus group is being conducted at the completion of two other delirium studies that were recently implemented at your site. The aim of this focus group is to obtain feedback about your experiences in using delirium screening, assessment and care processes, your thoughts about these processes, whether you believe these should be routinely integrated into daily care and how delirium recognition and assessment might be better achieved in specialist palliative care inpatient settings. This study is being conducted because delirium is under-recognised in palliative care inpatient settings, and it is hoped that the results of this study will inform and improve future palliative care practice.

### 3 Why have I been chosen?

You are being invited to participate in this questionnaire because you are a palliative care clinician who was involved in your unit's recent delirium screening or assessment activities and/or follow up patient care and have worked within the unit for more than three months.

### 4 Do I have to take part in the research?

If you do withdraw you will be asked to complete and sign a "Withdrawal of Consent' form, which is contained within this participant information sheet and consent form.

**10 What happens when the study ends?**

The results and findings of this study will be made available to each unit and all participants, once available.

**Part II – How is the study being conducted?**

**11 What will happen to information about me?**

By signing the consent form, you consent to the study coordinator and relevant research staff collecting and using personal information about you for the study project. Any information obtained in connection with this study that can identify you will remain confidential. Your personal information will be kept securely in a locked cupboard in a locked office at The Cunningham Centre for Palliative Care at the Sacred Heart Palliative Care Service, Darlinghurst and on password protected computers accessible only by study investigators. Your information will only be used for the purpose of this study and it will only be disclosed with your permission, except as required by law.

The personal information we will collect and use for this study is your name, role, site of work and length of time employed there. This information will be kept securely for a period of five years from the date of any publications arising from this study. After this time this information will be permanently destroyed.

It is anticipated that the results of this study will be published and or presented in a variety of forums. In any publication and/or presentation, all information will be provided in such a way that you cannot be identified, nor will your site's individual results be linked to your sites name. Sites will be identified as Site A, Site B, etc.

In accordance with relevant Australian and/or NSW privacy and other relevant laws, you have the right to request access to the information collected and stored by the study team about you. You also have the right to request that any information with which you disagree be corrected. Please contact the study team member named at the end of this document if you would like to access your information.

**12 What if something goes wrong?**

If you suffer any distress or psychological discomfort as a result of participating in this focus group, you should contact the study team as soon as possible, who will assist you in arranging appropriate support.

**13 Who is organising and funding the research?**

The study is being conducted by:

- Associate Professor Richard Chye, The Cunningham Centre for Palliative Care and Sacred Heart Palliative Care Service
- Professor Jane Phillips, The University of Notre Dame Australia, Sydney and The Cunningham Centre for Palliative Care
- Associate Professor Meera Agar, University of NSW and Medical Director of the Braeside Palliative Care Service
- Professor Liz Lobb, Calvary Health Care Sydney and The Cunningham Centre for Palliative Care
- Ms Annmarie Hosie, School of Nursing, University of Notre Dame, Sydney

- Site Investigator (name)

The study is being undertaken as one component of investigator Ms Hosie's doctoral research at The University of Notre Dame, Sydney.

No investigator or member of research staff will receive a personal financial benefit from your involvement in this study. The study is being partly funded by the University of Notre Dame, Australia through funding available for the direct costs of research. This funding does not create any conflict of interest for the investigators of this study.

**14 Who has reviewed the study?**

All research in Australia involving humans is reviewed by an independent group of people, called a Human Research Ethics Committee (HREC). This study has been reviewed and given approval by St Vincent's Hospital (Sydney) Human Research Ethics Committee.
The conduct of this study at <<insert name of site>>has been authorised by the <<insert name of organisation>>.

**15 Further information and who to contact**

If you would like any further information on this study you may contact Ms Annmarie Hosie on 0417292077.

If you would like to talk to someone not directly involved with the study for any further information regarding your rights as a study participant or should you wish to make a complaint to people independent of the study team, you may contact the St Vincent's Hospital (Sydney) Reserach Office on (02) 8382 2075 and quote the HREC reference number: HREC/13/SVH/152.

| Question | Who to contact | Phone / Facsimile |
|---|---|---|
| General questions or concerns during the study | Study Coordinator Ms Annmarie Hosie<br><br>Principal Investigator (for site) | Phone 0417 292 077<br>Facsimile + 61 2 8382 9518<br><br>Phone<br>Facsimile |
| Questions about the way the research is being conducted | HREC Executive Officer<br><br>Institutional Research Governance Officer | Phone +61 2 8382 2075<br>Facsimile +61 2 9332 4142<br>Phone<br>Facsimile |

THE UNIVERSITY OF NOTRE DAME AUSTRALIA

**PARTICIPANT CONSENT FORM**

| | |
|---|---|
| **Title** | ***Determining the feasibility and acceptability of delirium screening and assessment processes in specialist palliative care units*** |
| **Principal Investigators** | **Associate Professor Richard Chye**<br>**Professor Jane Phillips**<br>**Associate Professor Meera Agar**<br>**Professor Liz Lobb**<br>**Ms Annmarie Hosie**<br>**Site Investigator (name)** |
| **Site** | **Braeside/Sacred Heart/Calvary Health Care Sydney (only relevant site name will be inserted)** |
| **Protocol** | **V1** |

1. I have read the attached Participant Information Sheet outlining the nature and purpose of the research study and I understand what I am being asked to do.
2. I have discussed my participation in this study with the member of the study team named below. I have had the opportunity to ask questions and I am satisfied with the answers I have received.
3. I understand the focus group will be audio-taped.
4. I have been informed about the possible risks of taking part in this study.
5. I freely consent to participate in the research project as described in the attached Participant Information Sheet.
6. I understand that my participation is voluntary and that I am free to withdraw prior to the commencement of the focus group.

| Name of Participant | Signature of Participant | Date |
|---|---|---|
| Name of Witness to Participant's Signature | Signature of Witness | Date |

*Witness is not to be the Investigator or member of the study team nor their delegate
* Please note that in the event that an Interpreter is used, the Interpreter is not a witness to the consent process

| Name of Investigator | Signature of Investigator | Date |
|---|---|---|

*Participant will be provided with a copy of the Participant Information Sheet and this Consent Form*
*All parties signing the Consent Form must date their own signature*

THE UNIVERSITY OF NOTRE DAME AUSTRALIA

***WITHDRAWAL OF PARTICIPATION***

| | |
|---|---|
| **Title** | ***Determining the feasibility and acceptability of delirium screening and assessment processes in specialist palliative care units*** |
| **Principal Investigators** | **Associate Professor Richard Chye**<br>**Professor Jane Phillips**<br>**Associate Professor Meera Agar**<br>**Professor Liz Lobb**<br>**Ms Annmarie Hosie**<br>**Site Investigator (name)** |
| **Site** | **Braeside/Sacred Heart/Calvary Health Care Sydney (only relevant site name will be inserted)** |
| **Protocol** | **V1** |

I hereby wish to WITHDRAW my intent to participate further in the above research project and understand that such withdrawal will not jeopardise my future professional relationships with the study investigators.

Participant's Name (printed) _____

Signature _____

Date _____

In the event the participant decided to withdraw verbally, please give a description of the circumstances. Coordinating Investigator to provide further information here:

| |
|---|
| |

Coordinating Investigator to sign the withdrawal of consent form on behalf of a participant if verbal withdrawal has been given:

_____

Signature of Investigator _____

Date _____

*Participant will be provided with a copy of this Withdrawal of Consent Form*


**[Name/logo of local institution/s where research is being conducted to be inserted]**

# PARTICIPANT INFORMATION SHEET AND CONSENT FORM

## CLINICAL RESEARCH

**Study Title:**
**'Exploring nurses' capabilities and practices in recognising acute changes in patients' awareness, cognition and perception in specialist palliative care inpatient units, using Critical Incident Technique.'**

**(Short Title: The DePAC Study Number 4)**

### Invitation

You are invited to participate in a research study of nursing practice in palliative care inpatient settings, in the recognition and assessment of acute changes in patients' awareness, cognition and perception.

The study is being conducted by:

- Professor Jane Phillips, The University of Notre Dame Australia, Sydney and The Cunningham Centre for Palliative Care
- Ms Annmarie Hosie, PhD candidate, University of Notre Dame, Sydney
- Professor Patricia Davidson, the University of Technology, Sydney
- Associate Professor Meera Agar, University of NSW and Medical Director of the Braeside Palliative Care Service
- Professor Liz Lobb, Calvary Health Care Sydney and The Cunningham Centre for Palliative Care
- (Name of Site AI, Role, Site Name)

The study is being undertaken as one part of a doctoral research project, at The University of Notre Dame, Sydney.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

### 1. 'What is the purpose of this study?'

The purpose is to identify effective practices of specialist palliative care nurses in the recognition and assessment of acute changes in inpatients' awareness, cognition and perception, using semi-structured participant interviews to gather information. As acute changes to patients' awareness, cognition and perception are known to be both prevalent and under-recognised in palliative care inpatient

populations, these symptoms and their impact on patients are significant in palliative care nursing practice.

This study will inform a future pilot nursing intervention within the doctoral research.

**2. 'Why have I been invited to participate in this study?'**
You are eligible to participate in this study because you are a registered nurse working in a specialist palliative care inpatient unit in NSW.

**3. 'What if I don't want to take part in this study, or if I want to withdraw later?'**
Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect your employment now or in the future, nor will it affect your relationship with the organisation you work for.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

**4. 'What does this study involve?'**
If you agree to participate in this study, you will be asked to sign the Participant Consent Form and to give some demographic, role and individual practice information.

You will then be provided with a short written case scenario of a palliative care inpatient experiencing acute changes in awareness, cognition and perception and asked to recall a similar situation you have observed or experienced recently in your own clinical practice. The case scenario will be provided to you at least half an hour, but no more than four hours, before the interview.

Once you have had this time to read the case scenario and think about any similar clinical experiences, questions relating to nursing care of a patient experiencing similar symptoms will be asked of you, in a short face-to-face or telephone audiotaped interview. It is anticipated that most interviews will take between 15-20 minutes.

**5. 'How is this study being paid for?'**
The study is being partly funded by the University of Notre Dame, Australia through funding available for the direct costs of research. This funding does not create any conflict of interest for the investigators of this study.

**6. 'Are there risks to me in taking part in this study?'**
The risks of this study may include potential inconvenience being approached to participate in the study and being asked to answer a series of questions. There may be a small risk of distress associated with answering the questions related to

your palliative care clinical experience. If this happens, you are encouraged to speak with the researcher about your concerns during the interview or later by telephone, and/or with your manager who can give further advice on the support services available to you.

**7. 'Will I benefit from the study?'**
You may not experience any direct benefit from the study. However, some nurses who participate may obtain benefit from the study because of the opportunity to reflect on practice and share stories, experiences and expertise.

**8. 'Will taking part in this study cost me anything, and will I be paid?**
Participation in this study will not cost you anything. You will not be reimbursed for your time or travel expenses.

**9. 'How will my confidentiality be protected?'**
In the conduct of this study only the researcher Ms Hosie will know whether or not you are participating in this study. Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researchers named above and the Human Research Ethics Committee (HREC) for monitoring purposes will have access to your identifiable details and results, which will be held securely at The Cunningham Centre at The Sacred Heart Palliative Care Service, Darlinghurst.

**10. 'What happens with the results?'**
If you give us your permission by signing the consent document, we plan to publish the findings in a peer-reviewed journal, and present and share findings at relevant palliative care or delirium conferences and palliative care peak organisations. The processes and results of this study will also be disseminated as a chapter within a PhD thesis.

In any publication, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish.

**11. 'What should I do if I want to discuss this study further before I decide?'**
When you have read this information, the researcher Ms Hosie will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact her on 0417 292 077 during office hours.

**12. 'Who should I contact if I have concerns about the conduct of this study?'**
This study has been approved by St Vincent's Hospital HREC. Any person with concerns or complaints about the conduct of this study should contact the

Research Office who is nominated to receive complaints from research participants. You should contact them on 02 8382 2075 and quote [*HREC project number*].

The conduct of this study at the [*name of site*] has been authorised by the [*name of organisation*]. Any person with concerns or complaints about the conduct of this study may also contact the [*Research Governance Officer* or *other officer*] on [*telephone number*] and quote reference number [*insert HREC reference number*]

**Thank you for taking the time to consider this study.**
**If you wish to take part in it, please sign the attached consent form.**
**This information sheet is for you to keep.**

THE UNIVERSITY OF NOTRE DAME AUSTRALIA [

***[Name/logo of local institution/s where research is being conducted]***

**CONSENT FORM**

[To be used in conjunction with a Participant Information Sheet]

**'Exploring nurses' capabilities and practices in recognising acute changes in patients' awareness, cognition and perception in specialist palliative care inpatient units, through Critical Incident Technique'**

**(Short Title: The DePAC Study Number 4)**

1. I,.....
of.....
agree to participate as a participant in the study described in the Participant Information Sheet set out above.

2. I acknowledge that I have read the Participant Information Sheet, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the information sheet has been explained to me to my satisfaction.

3. Before signing this consent form, I have been given the opportunity of asking any questions relating to any possible harm I might suffer as a result of my participation and I have received satisfactory answers.

4. I understand that I can withdraw from the study at any time without prejudice to my relationship to the (Site Name).

5. I understand the interview will be audiotaped.

6. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.

7. I understand that if I have any questions relating to my participation in this research, I may contact Ms Annmarie Hosie on telephone 0417292077, who will be happy to answer them.

8. I acknowledge receipt of a copy of this Consent Form and the Participant Information Sheet.

Complaints may be directed to the Research Office, Phone: 02 83822075

| **Signature of participant** | **Please PRINT name** | **Date** |
|---|---|---|
| | | |
| **Signature of witness** | **Please PRINT name** | **Date** |
| | | |
| **Signature of investigator** | **Please PRINT name** | **Date** |
| | | |

**[Insert name/logo of local institution where research is being conducted]**

**'Exploring nurses' capabilities and practices in recognising acute changes in patients' awareness, cognition and perception in specialist palliative care inpatient units, through Critical Incident Technique'**

**(Short Title: The DePAC Study Number 4)**

## REVOCATION OF CONSENT

I hereby wish to **WITHDRAW** my consent to participate in the study described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with the **[insert name of entity]** or my medical attendants.

Signature Date

Please PRINT Name

The section for Revocation of Consent should be forwarded to Ms Annmarie Hosie, C/O School of Nursing, The University of Notre Dame, Sydney, PO Box 944 Broadway, NSW, 2007.

# APPENDIX 6

## *ANZSPM/PCNA JOINT SUBMISSION TO THE AUSTRALIAN COMMISSION FOR QUALITY AND SAFETY OF HEALTH CARE*

ANZSPM/PCNA Submission to ACSQHC re Delirium Standard: Prepared by Associate Professor Meera Agar, Professor Jane Phillips and Ms Annmarie Hosie, 30 June 2015, on behalf of The Australian and New Zealand Society of Palliative Medicine, and Palliative Care Nurses Australia.

# ANZSPM/PCNA Joint Submission to the ACSQHC National Consultation on the draft Delirium clinical care Standard, June 2015.

**How well does each quality statement describe the key aspects of care?**

*Quality standard 1 and 2:*

We believe these standards describe the key aspects of optimal delirium care. Australian data highlights that more than 50% of Australians die in acute hospitals[1] and only 15% in specialist palliative care units.[2] This reality makes these standards applicable to all people admitted to sub-acute and acute facilities with palliative care needs. The palliative care inpatient population is at high risk of delirium due to advanced illness, older age (mean age 72.2 years), associated medical comorbidities and concurrent illness.[1] Psychoactive medications are commonly used for relief of symptoms associated with life limiting illness, such as pain and breathlessness. These medications increase the risk of palliative care patients developing incident delirium.

Studies that screened at least daily for delirium have found that this syndrome is present in 33-45% of all palliative care inpatients.[3,4] The prevalence of delirium in palliative care inpatients ranges from: 13-42% at admission, 26-62% during admission and 59-88% within the last weeks of life. Hypoactive delirium, which is challenging to recognise, is the most prevalent delirium subtype present in 68-86% of cases.[3] Up to 50% of episodes of delirium in palliative patients are highly reversible.[5,6]

Delirium under-recognition, risk, prevalence, iatrogenic causes, and potential for reversibility, combined with the increasing acuity of the patients admitted for palliative care management to the acute and subacute settings (inpatient generalist and specialist palliative care units in Australia), all highlight the importance of systematic approaches to delirium recognition and assessment for this patient population.[1] A thorough bedside assessment using validated tools is critical to plan care and confirm the diagnosis with the palliative patient and their family. It is only then that the clinician can determine if the patients' advanced illness makes their delirium irreversible or if particular investigations and interventions are not in accordance with patients' needs, values or wishes.

Brief, simple, observational delirium tools exist and can be effectively used to assess for delirium in palliative care patients, given sufficient user training.[7,8] Yet specialist palliative care units have not established effective processes to recognise, assess and respond to patients' cognitive impairment.[9] As a consequence, delirium is under-recognised and inadequately addressed in the palliative care setting, as in other acute care settings.

*Quality standard 4:*

Quality Standard 4 applies even in the case of delirium in the terminal phase, where causes requiring simple interventions that are not burdensome to the patient, such as a medication change, can still be utilised. The selection of appropriate delirium interventions in palliative inpatients needs to be informed by the findings of a comprehensive delirium assessment, consideration of the illness trajectory and an understanding of the patients' needs, values and wishes.

*Quality standard 6:*

The anti-psychotics risperidone and haloperidol should be avoided in palliative care patients with delirium, as a recent randomised controlled trial in the palliative population demonstrated these commonly used medications increased the severity of agitated delirium symptoms.[10] This differs from the Quality Standard 6, which suggests antipsychotics may be administered in the event of patient distress unrelieved by non-pharmacological management. Anti-psychotics may increase the distress of palliative care patients with delirium.

*Quality standard 7:*

Around half of palliative care inpatients die during their admission and half are discharged.[1] This means that discharge planning, including reducing the risk of delirium and complications from it, is an important component of care for many inpatients who are returning home or to an aged care facility.

**What factors (barriers) currently prevent the care described in the Clinical Care Standard from being achieved? Provide further comment, or specify any other relevant factors.**

Barriers to implementation in specialist palliative care inpatient settings may include clinician attitudes that delirium is inevitable and innocuous for patients at the end of life.[11] Other barriers include: clinicians' delirium knowledge deficits; the need to determine which low burden delirium tools are the most valid and feasible for use within this patient population; and for teams to adapt to a more interdisciplinary (rather than the current multidisciplinary) approach to patient care, family engagement and clinician education in delirium.[9]

**What factors (enablers) will support the practical application of this Clinical Care Standard? Provide further comments (such as details of any existing resources that this Clinical Care Standard might link into).**

Factors that will support the practical application of this Clinical Care Standard are those that address the specific barriers identified above, including: interdisciplinary practices and delirium education resources and opportunities; better communication with patients and families about delirium; and the trialing and testing of low burden delirium tools for this inpatient population.

**How relevant are the suggested indicators in supporting the local monitoring of the quality statements? Provide any comments you may have and evidence to support any changes. What improvements would support data collection for the suggested indicators?**

The Palliative Care Outcomes Collaboration (PCOC)[1] works with clinical palliative care services nationally to measure and benchmark quality palliative care. However, at this time the suite of PCOC indicators does not include a daily delirium screening score. There are opportunities for delirium to be integrated into this suite of indicators and for these to be used to monitor the quality of delirium care in this setting.

[1] http://ahsri.uow.edu.au/pcoc/

**How should the Clinical Care Standard be shared? (Including web and printed resources). Please be as specific as possible.**

Ideally the standards ought to be placed on a wiki platform (refer to Australian Cancer Pain Guidelines[12] as an exemplar) so they can be readily updated as new evidence emerges. The dissemination of the standards and guidelines needs to be part of a wider implementation process.

**Do you have any other comments about the Clinical Care Standard?**

We applaud the Commission for developing these standards, which provide a clear pathway for the optimal management of delirium for patients admitted to the Australian acute care setting. Our submission calls for:

1. The inclusion of patients receiving palliative care within the indicators of the proposed delirium clinical care standard. The draft standard proposes to exclude "**patients with delirium tremens** (substance withdrawal delirium) or **terminal delirium** (delirium in patients receiving palliative care) (p.7). We believe that the ACQSHC delirium clinical care standards are highly relevant to the care of patients with a palliative diagnosis, regardless of the setting where they are receiving care. Many patients receiving palliative or end of life care are cared for within the acute general hospital setting[13], which will be required to meet the delirium clinical care standard. There is no evidence that palliative care patients require a 'specialised approach' to delirium care per se. The most appropriate approach to delirium care for the individual palliative care patient is determined through comprehensive assessment, which is consistent with the proposed standard; and appropriate management, which is likely to be primarily a non-pharmacological approach. Exclusion of patients receiving palliative care from the proposed delirium clinical care standard is therefore an artificial and unnecessary separation. All patients receiving palliative or end of life care, regardless of care setting, require proactive approaches to prevent, recognise, assess and effectively and supportively respond to the problems associated with chronic or acute cognitive impairment. The removal of the imprecise descriptor 'Terminal delirium',

which is not included within internationally accepted diagnostic criteria (DSM-V) [14]. We believe that the use of this term contributes to conceptual confusion and inadequate assessment of patients experiencing delirium. If it is to be used, it needs to be clearly defined.

## References

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3. Hosie A, Davidson PM, Agar M, et al: Delirium prevalence, incidence, and implications for screening in specialist palliative care inpatient settings: A systematic review. Palliative Medicine 27:486-498, 2013

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5. Lawlor PG, Gagnon B, Mancini IL, et al: Occurrence, causes, and outcome of delirium in patients with advanced cancer: a prospective study. Archives of Internal Medicine 160:786, 2000

6. Leonard M, Raju B, Conroy M, et al: Reversibility of delirium in terminally ill patients and predictors of mortality. Palliative Medicine 22:848-854, 2008

7. Ryan K, Leonard M, Guerin S, et al: Validation of the confusion assessment method in the palliative care setting. Palliative Medicine 23:40-45, 2009

8. Detroyer E, Clement PM, Baeten N, et al: Detection of delirium in palliative care unit patients: A prospective descriptive study of the Delirium Observation Screening Scale administered by bedside nurses. Palliative Medicine 28:79-86, 2014

9. Hosie A, Lobb E, Agar M, et al: Identifying the Barriers and Enablers to Palliative Care Nurses' Recognition and Assessment of Delirium Symptoms: A Qualitative Study. Journal of Pain and Symptom Management 48:815-820, 2014

10. Agar M, Lawlor P, Quinn S, et al: Phase III randomized double-blind controlled trial of oral risperidone, haloperidol or placebo with rescue subcutaneous midazolam for delirium management in palliative care, Australian and New Zealand Society for Geriatric Medicine Annual Scientific Meeting. Perth, Australasian Journal on Ageing, 2015, pp 33

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12. Australian Adult Cancer Pain Management Guideline Working Party: Cancer pain management in adults. Sydney: Cancer Council Australia 2014

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14. American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). Arlington, VA, American Psychiatric Publisher, 2013